PROVIDING A CONSTRUCTIVE HOSPITALIZATION EXPERIENCE FOR A YOUNG CHILD AND HER MOTHER

CHARLES SWENSON

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PROVIDING A CONSTRUCTIVE HOSPITALIZATION EXPERIENCE FOR A YOUNG CHILD AND HER MOTHER

Charles Swenson

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Charles L. Swenson

Signature of Author

4/20/76

Date

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PREFACE

Thoughts of this project began two and a half years ago, when as a first year Medical Student I was beginning my first evening in the Pediatric Emergency Room with an attending physician. Within half an hour of my arrival, a six-year old girl was brought by an ambulance with fractures of her mandible (jaw) and femur (thigh) sustained in a car accident. She was whisked into the X-Ray Suite, then wheeled into an adjacent room to await the radiographic results. I noticed her there and walked in. It was a large, dark room filled with imposing medical apparatus. She was crying; her screams of "Mama!" were muffled by the painful fractured jaw. Her face and clothes were bloody and her eyes were wide with fright as I approached. Most upsetting of all was that she had been left alone in that room, and would in fact have remained so had I not happened by. I decided to stay by her side, both as a friendly supportive figure and as a student curious about what happened to children who entered the hospital via the Emergency Room.

She and I established a means of communicating by which I would speak or ask questions, or try to interpret what she wanted, and she would nod yes or no; her mouth was too painful for speaking. Her parents were in the Waiting

Room. They had been told to wait out there while their daughter had X-Rays taken, that they could then be with her again. But no one informed them that she was already finished. When I inquired on their behalf, I was told that the girl would now be sent to the Pediatric Intensive Care Unit; the parents could see her after she was there. I explained this to the parents who were frightened, very upset, and felt left out.

I stayed with the girl as we went up the elevator and to the ICU. Her parents took another elevator and waited in the hallway outside the ICU as the nurses washed the patient and changed her clothing. Then the orthopedists set her leg in traction, throughout which she screamed in pain. Finally the parents were allowed in. They stayed by her side for many hours as she wept, and they comforted her.

The role that I played that night, and the highly charged feelings that I experienced, contained in a nutshell a realm of concerns about medicine and hospitals that have stuck with me and which have inspired this project. On the one hand I identify with and empathize with patients and their families undergoing stressful life crises. And on the other hand I am learning to identify myself as a doctor, and to understand the pressures on and priorities of doctors and nurses in hospitals. So that when a patient and family under duress are in the hospital, I find myself identifying

with both sets of people. And when it seems to me that the hospital people are not responding sensitively to the patient and family, I feel highly moved to do something about it: to respond sensitively myself, to talk with other hospital personnel, to determine why it happened, and to work toward a change in the priorities of the hospital system. This project attempts all of these things.

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CHAPTER I

INTRODUCTION, OBJECTIVES, AND METHODOLOGY

Over the past three decades, a good deal has been learned about the hazards of hospitalization for the very young child: which children are most vulnerable, which aspects of the experience are apt to be most distressing, and what kinds of psychological disturbances are associated with hospitalization. Concurrently, significant steps have been taken in applying that knowledge in most hospitals towards the total goal stated in 1945 by Milton Senn, "of restoring physical function and mental well-being and of preventing as much as possible all psychological and somatic residua." (Senn, 1945) In fact, hospitalization has been found in some cases to be a strengthening and maturing experience for the child and family. (Solnit, 1960; Vernon et al., 1964; Prugh, 1953; Ferholt and Provence, 1976.)

However, there exists considerable agreement that our usual Pediatric hospital care still does not adequately reflect the lessons we have learned. Escalona wrote in 1972,

> Ordinarily, in matters medical at any rate, information about the cause of pathology quickly leads to the development of new techniques in treatment, management, and prevention. Not so with respect to the mental health aspects of medical practice. In

> respect to how we deal with children in hospitals, there is a wide gap between what we know would be more adequate, and what we actually do. (Escalona, 1972)

James Robertson, a Scottish Social Worker and Psychoanalyst who has devoted many years to filming and writing about the effects of hospitalization and separation from parents on very young children, wrote:

> In recent years there has been a marked trend towards "humanizing" the care of young children in hospital. Amenities are being improved--there is increased visiting, provision of playrooms and teachers, and general brightening of surroundings--but it is clear that these are rarely introduced as part of a coherent approach to meeting the child's emotional needs. (Robertson, 1970)

In the introduction to their recent book, Petrillo and Sanger wrote:

> Although today we are quite sophisticated regarding the psychological responses of children to illness and hospitalization, it is striking to note the discrepancies between what we know and what we practice in the hospital environment. Indeed, we need to know more, and we need to encourage more research. But, at this time, it is our belief that <u>the most compelling need is for the application of existing knowledge by those most intimately involved in patient care</u>. (My underlining; Petrillo and Sanger, 1972)

Why such a gap between knowledge and practice has arisen and persisted so stubbornly will be subject to analysis in the final chapter.

The project described in this thesis was addressed to this "most compelling need." During April and May of 1975, my colleagues and I attempted to fully apply knowledge to

practice in the hospitalization of a fifteen month old child admitted for cleft palate surgical repair.* We learned what we could from the literature in Nursing, Social Work, Pediatrics, Child Psychiatry, and Psychology.** We pooled our own experiences and common sense. Before beginning, I observed, videotaped, and studied systematically the "usual" hospital management of a seventeen month old child admitted for cleft palate surgery to the Pediatric ward in our hospital. In the second hospitalization, the child and mother were admitted under circumstances that were as ideal as possible: a small, relatively quiet and secure Pediatric Research Unit staffed by nurses tremendously experienced and knowledgeable in child behavior and development. We tried to implement a coherent psychological management plan, enmeshed with the physical treatment plan, geared to that particular child and family, spelled out in details, and responsive to changes in the physical and psychological hospital course. We acted with full understanding that the physical layout, the staffing patterns, and the enormous

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*My colleagues, in planning and implementation were: Julian Ferholt, M.D., Child Psychiatrist; Mrs. Mary Carey, R.N., Head Nurse of Fitkin 3 Research Unit; Marianne Miranda, R.N.; Jane Mueller, R.N.; Maureen Kangley, R.N.; Peggy Sands, R.N.; and Lynn Budris, R.N. It was truly a collaborative effort.

**A review of relevant literature and a historical perspective on children in the hospital are presented in Part 1 of the Appendix.

demands on the workers on typical Pediatric wards as they presently exist would make some components of our idealized plan nearly impossible to implement. Our hopes were to realize the ideal in one case and monitor the results, in the hope that a clearer perception of the ideal would more accurately inform our continuing efforts to humanize the hospital environment.

Objectives

The present investigation was designed in order to:

1. specify the nature of the immediate reactions and modes of adaptation of child and parents during a short term hospitalization of the child;
2. characterize the readaptation of the child and parents to the home environment following the hospitalization;
3. specify, on the bases of 1 and 2, the nature of the stresses upon the child and parents as a result of hospitalization;
4. formulate a treatment program for such a child, based on the findings of 1, 2, and 3 with intentions of minimizing the occurrence of overwhelming stressful experiences and maximizing the possibility of coping with the stresses in a growth-promoting manner;
5. carry out the treatment formulation in the same hospital on another child, similar in age, diagnoses, treatment, and in other aspects if possible;
6. apply the investigatory procedures, developed and used in the first case, to the second case, evaluating the success of the intended beneficial hospitalization.

Methodology

Previous research in this area has applied a wide variety of methods, along a spectrum from impressionistic clinical reports to formal, objective scales in which preselected categories of behavior are coded and rated. It was our opinion that the impressionistic clinical reports often lack the presentation of sufficient behavioral details to demonstrate the data underlying the impressions. And the formal, objective methods often strip the recorded behaviors from their individual and social contexts, rendering their interpretation difficult. The emphasis of the present investigation is on a multi-method approach documented most importantly by very detailed, systematized, continuous observation and evaluation of the child and family before, during, and after hospitalization. In addition to the continuous observation and recording, an attempt was made to quantify some aspects of the data, most importantly with serial developmental evaluations of the child, but also with serial Child Behavior and Parental Anxiety Questionnaires. Because of the full time commitment required of the author by each case, and because of the limits of time and resources that framed the project, it must be viewed as a pilot effort for more extensive investigations.

The limitations of studying only two cases, one with an intervention and one without, are obvious. A contrast between the responses of the two to hospitalization could not

with full confidence be attributed to our interventions; many more similarly treated cases would be required to be sure that we made a difference. Although a comparison between the two cases may be highly suggestive, it is not the main thrust of this thesis. In our view, the first case served three purposes in preparation for the second: (1) as a source of data regarding the stresses of a usual hospitalization and their potential for traumatic impact; (2) as an example of some means to minimize trauma; and (3) as an opportunity to gain experience in applying the methods we had chosen.

The comparisons we made were not between one case and the other; but rather were between each child and family prior to admission and the same people after hospitalization. The extensive profile of the subjects before hospitalization and the careful documentation throughout the experience made this technique of using each case as its own control quite productive.

Subjects

The two subjects were chosen from a list of children between six months and three years of age to undergo elective surgery during the spring of 1975, with the additional qualification that their hospitalizations not overlap in time. Our objectives made a close match between subjects preferable but not necessary. We were aware that our selection process made a well-matched pair unlikely, but we were

fortunate in finding two cases matched closely in age, sex, state of physical and psychological health, family structure, socioeconomic class, diagnosis, surgical treatment, projected duration of hospitalization, and approximate distance between home and hospital. In Chapter III rather detailed profiles of each child and family are presented.

Settings of Study

The subjects were studied in their homes in the periods before and after hospitalization, and in the hospital during their eight days there. The home settings will be characterized in Chapter III. The first child was admitted to the usual Pediatric ward for children of her age; and the second was admitted to a Pediatric Research Unit in the same hospital, because it was a smaller, more intimate setting with a higher nurse:patient ratio. The two hospital settings are described in Chapter IV.

Investigative Techniques

The general strategy of the investigative methods was to gain, first of all, a thorough picture of past and present family and child functioning. The past history, gained mostly through the initial parent interview and the child's Pediatric records, had to include the child's growth and development, past experiences with and reactions to doctors and hospitals, the parents' early feelings about the child and significant experiences with her, their expectations for

her, their relationships to their parents, and so on (see Part 2 of Appendix for Initial Parent Interview). To gain a picture of the baseline of present functioning, we had to include not only the child's typical daily schedule of eating, sleeping, playing, which we could learn from the interview, but also needed a more intimate picture of her usual ways of relating to herself, her surroundings, her parents, unfamiliar people, brief separations, delayed gratification and other kinds of stress. We needed also to know what kind of nurturing environment she had come to expect, to depend on; how she could expect to be comforted, to be responded to when she cried or when she spoke. Systematized naturalistic observations in the home and developmental evaluations at the time of admission were the crucial methods for meeting these objectives. They were supplemented by brief informal interviews with the parents during home visits, by a questionnaire administered to the parents, the SCL-90, designed to provide a measure of anxiety and depression, and a Child Behavior questionnaire filled out by the parents (see Part 2, Appendix).

All of the same techniques were then reapplied during the hospitalization in addition to observations by nurses and the surgeon. We could in this way see clearly what the changes were, in the usual behaviors and interactions of child and parents, in the usual nurturing environment, and we could see how the family coped with the change.

Finally, we applied the same techniques again at the home after discharge, studying the return to the old patterns of experience, or the establishment of new ones. We hoped, by such close continuing data-gathering, to see what the changes were that presumably resulted from the hospital experience. Videotaping, which preserved the experience before, during, and after hospitalization, was used to provide a supplement to the recordings and subjective memory. To this predetermined framework of investigative methods, we applied a clinical method as we proceeded. That is, we formulated and refined our ideas as we went, pursuing in more detail, through interviews and observations, areas of interest and relevance suggested as the data accumulated.

We present here the time sequence of the application of our various methods, followed by discussions of each one.

5 Weeks Prior to Admission	Contact surgeon, gain his consent to contact patient and family.
4 Weeks Prior to Admission	Contact family, explain project, invite participation; parents sign consent form.
2 Weeks Prior to Admission	1. Extensive Initial Parent Interview 2. Interview with surgeon to discuss: a. Nature of child's defect (cleft palate); b. Nature of necessary surgery; c. Preoperative and postoperative nursing orders.
1 Week Prior to Admission	1. 3 visits to home of patient, of which: a. 2 visits were for observation and recording of child and child-parent interaction; b. 1 visit was for videotaping of child and parents;

		c. all 3 visits included brief informal interviews with parents; d. 1 visit included administration of SCL-90 Questionnaire and Child Behavior Questionnaire.
	2.	Study of the child's pediatric records, in the hospital and in the pediatrician's office.
Day of Admission	1.	Developmental evaluation of child.
	2.	Observations, with descriptive recording, throughout admission until child put to bed for the night.
	3.	Videotaping session.
During Hospitalization (8 days)	1.	Daily observation sessions, 2 hours per day or longer, with descriptive recording.
	2.	Surgery performed on day following admission: observation and descriptive recording of pre-anesthesia period and post-operative awakening period and return to ward.
	3.	Videotaping session one day following surgery.
	4.	Administration of SCL-90 and Child Behavior Questionnaires 2 days following surgery, to parents.
	5.	Informal interviews with surgeon to gain his impressions of child's surgical course and psychological adjustment.
Day of Discharge	1.	Developmental evaluation of child.
	2.	Interviews with nurses involved in patient's care, to gain impressions of child and parent adjustment and response to hospitalization.
	3.	Observation and descriptive recording of entire discharge procedure.
During the 2 Weeks Following Discharge	1.	3 visits to home of patient, of which: a. 2 visits were for observation and recording of child and child-parent interaction; b. 1 visit was for videotaping of child and parents; c. all 3 visits included brief informal interviews with parents; d. 1 visit included administration of SCL-90 and Child Behavior Questionnaire.

2. Interview with surgeon concerning child's and parents' responses and adjustment to hospitalization.

Direct Observation

This technique required that the observer be as unobtrusive as possible so as to minimally alter the usual behaviors and interactions. The parents undoubtedly remained aware of me most of the time, though they seemed to be quite at ease and at times almost unaware of my silent presence in the far corner. The children, quite distracted by me at times, seemed most of the time to simply forget that I was there. The most delicate task I had was in responding to the child's approaches in a manner that neither invited more and more contact nor intimidated and frightened her by its unresponsive strangeness. This presented little problem most of the time.

The recording of my observations was performed in two ways. Time was divided into five minute segments. The first four minutes were spent in a flowing diary-type recording of what I saw: the behaviors, their context, relevant factors, the affects, the language. During the fifth minute, I rated the preceding four minutes of behavior in five categories: Gross Motor Activity, Interaction with Toys and Inanimate Objects, Interaction with People, Affect and Anxiety, and Language and Communication. The categories were adapted from the Yale Revised Developmental Schedule and the "Dimensions of Infant Behavior" in Escalona's Roots of Individuality

(1968). I devised the rating scale, which evaluated the amount and intensity of each affect, interaction, or the amount and nature of the communication (see Appendix, Part 2, for details). Because of this and because no other investigator was using the scale, the observations as data must be considered subject to the limitations of the single observer method. The recording system was devised to introduce a systematic approach into the observations, forcing a continual recording and evaluation of behaviors of several kinds. The scale was to have value in comparing observations prior to hospitalization with those afterwards. I had gained experience in using the recording system in observing infants in the hospital for a total of 20 hours prior to this project.

Observations were made and recorded during hospitalization, for more than two hours per day, in a flowing, descriptive manner.

Nursing Observations

During the second hospitalization, the nurses on the Research Unit also made direct observations, recording them frequently in a systematic format designed by them and myself. (See Appendix, Part 2.) The recordings were divided into categories of Child Activity, Investment in Toys, Emotional State, Communication, Response to Me, Response to Mother, Comments on Mother. These were regarded as raw data along

with the author's observations, in gaining a composite view of the family's experience.

Developmental Evaluation

These were performed just before and just after hospitalization by the child psychiatrist (JF), trained and experienced in the use of the Yale Revised Developmental Schedule (see Appendix, Part 2). The data from the test situation can be classified as (1) a quantitative assessment of the child's developmental level, and (2) as qualitative assessment of the child and child-parent relationship in a structured situation (see Provence and Lipton, *Infants in Institutions*, 1962).

Interviews

1. The first interview with the parents, two weeks prior to admission, with the intention of obtaining a detailed family-child profile, was semi-structured and lasted two hours (see Appendix, Part 2, for format). It also served the purpose of familiarizing the interviewer with the parents and child, and familiarizing the parents and child with the interviewer so that later, as an observer, he would be less intrusive in the home.
2. Later interviews with parents, during visits to the home and during hospitalization, were more informal, unstructured, and brief. They were a means of learning a little more about the parents' feelings and their perceptions of their child and the hospital.

3. The interview with each nurse involved in the child's care, done after discharge, was brief and structured (see Appendix, Part 2, for outline). The intention was to gain the nurses' impressions of the child, the family, the effect of the hospitalization on the child and family, and their views in more general terms about hospital care and its effects.

4. In the first case only, a close friend of the mother was in close contact with her during the experience, and even visited the hospital with the mother on two occasions. On those occasions and after the hospitalization, the friend was interviewed so as to gain another picture of how the mother and child experienced the hospitalization.

5. The first interview with the surgeon, about two weeks prior to admission, was a long, detailed inquiry into the nature of the cleft palate defect, its effects on early child care and behavior, its surgical treatment, and the nursing and medical orders before and after surgery. It also served as a time to recruit the surgeon's support of the project. Later interviews with the surgeon, during hospitalization and after, were designed to learn of his impressions of the child's response to the surgery and hospitalization, psychologically as well as physically.

Videotape

Videotaping was used to serve two different purposes during the second hospitalization (the quality of the videotape in the first case was severely compromised because of the inaccessibility of good equipment). It was used first of all to preserve a record of the behavior of the child and the child-parent interaction in semi-structured situations before and after hospitalization. This was a great aid in comparing the pre-hospital and post-hospital behavior in the home environment. The taping sessions in the home each took a total of 30 minutes of actual taping, including segments from five different situations: (a) child eating a meal; (b) child free at play; (c) child attempting a difficult task with parental assistance; (d) child at play with parents; (e) and child alone while parents leave the house for several minutes. The second use to which videotaping was put was the preservation of segments of the second hospitalization itself, focusing mostly on the planned interventions, and the child's and parents' responses.

Questionnaires

1. SCL-90. In seeking a relatively objective and reliable measure of the changes in the parents' levels of anxiety or depression throughout the hospitalization and afterwards, the author sought advice from a psychologist, Dr. Myrna Weissman, who recommended serial application of the SCL-90. This was

administered to the parents before, during hospitalization (twice in the second case), and after discharge.

2. Child Behavior Questionnaire. (See Appendix, Part 2.) This was designed by the author and the child psychiatrist, J. F., mostly derived from a questionnaire used by Vernon, et al. (1966) to study responses of children to hospitalization, as adapted to the behavior of children 15 to 17 months old. It was a systematic way of recording the parents' impressions of their child before, during, and after hospitalization. Its value was in watching for changes in the individual items throughout the experience. The parents' perceptions could in this way be compared to those of the observer, the nurses, the child psychiatrist, and the surgeon, for a more reliable overall evaluation.

Interventive Techniques

We tried to learn from the literature, from our own past experiences, and from the first case, what was most stressful and traumatic about hospitalization, and what would be most beneficial to the child undergoing surgery. We then applied this knowledge in the second case, through numerous interventions. As the story of the hospitalization is told in detail in Chapter VI, including the planning and execution of interventions, these techniques will not be discussed here.

The following four chapters present the results of this project. Chapter II presents the subjects, Chapter III

presents the two hospital wards, Chapter IV presents the story of the first hospitalization, and Chapter V presents the story of the second hospitalization. In Chapter VI a summary and a discussion of implications of this project are presented.

CHAPTER II

THE CHILDREN AND THEIR PARENTS*

Two attractive girls of approximately the same age (15 and 17 months), each the only child of young parents in a middle class setting, each born with a small cleft of the soft palate, each healthy and well developed and primarily cared for by her mother, were each electively scheduled for a surgical palatal repair by the same surgeon in the same hospital one to one and a half hours from their homes. The similarities ended there.

The two children were unique individuals, each having certain vulnerabilities, particular coping strengths, and characteristic styles of expression. They lived in different families which would respond to a stressful event like hospitalization in their own ways. They were to be admitted to different wards, where the approach to their care would be markedly different.

Through interviews, questionnaires, structured developmental examinations, and many hours of detailed systematic observation before, during, and after the hospitalization, we captured as best we could, the continuous experience of each

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*The names and places of residence of the children and their parents have been disguised in order to preserve confidentiality.

child and family over a month's time. We came to know these people well: how they anticipated, experienced, and looked back on the time in the hospital; what was hardest for them, how they coped with that, how they responded to the hospital staff and to ourselves.

In this chapter, we would like to acquaint you with these people so that you can try, as we are trying, to understand what the hospitalization meant to them. We begin with the Kelly family (first hospitalization) and will follow with the Burns (second hospitalization), using approximately the same structure of presentation in each case.

Mr. and Mrs. Kelly and their 17 month old daughter Brenda live in eastern Connecticut in a housing development: modern quadruplexes, duplexes, and single family houses neatly spaced among large, well-groomed yards and winding streets. On a sunny day, the neighborhood is alive with activity, playing children to be seen everywhere. The Kelly's apartment, one of four in a quadruplex, is very much like all others in the development. Downstairs are a living room and kitchen, upstairs a bathroom and two bedrooms. It is furnished modestly and tastefully, and usually is kept tidy and clean. Most often the T.V. or radio is playing and casual visits by neighbors are frequent. The atmosphere includes lots of joking and teasing between the parents, brief affectionate scenes initiated by Mrs. Kelly, a scarcity

of low-keyed or serious conversation, and at times, a somber, lethargic, depressed tone.

Mr. and Mrs. Kelly, 24 and 22 years old respectively, moved to this setting two to three years ago from Texas, where both have always lived. The two had quite different family backgrounds. Larry Kelly was adopted at the age of five years and has no knowledge of his life before that or of his biological family. His parents adopted one more son after him, and had a girl born to them ten years younger than Brenda. He has never felt, and is not now, close to any of them. He was in general, as a child, somewhat lonely, depressed, and distant from other people. He took a great interest in mechanics and electronics that has persisted to the present time. His depression was most serious in his senior year of high school when he overdosed on Librium just before his final exams. He was hospitalized for two to three weeks and has had no psychiatric treatment or contact since then. He describes himself now as a somewhat lonely, nervous person who stays on the go all the time "like a hyperactive kid." He had no formal education beyond high school but hopes to learn more electronics in school after his six year Navy commitment.

Sue Kelly comes from a close family with two parents and a younger brother. She still is close to all of them, is homesick and frequently telephones them in Texas. She finished high school, went to one semester of college before

marrying Mr. Kelly and moving with him to eastern Connecticut for his Navy duty, and hopes someday to return to school to study history. As she recalls, her childhood was a happy one with lots of family activities. She was hospitalized once as an eight year old child when she was to have a tonsillectomy; she reported, "I was scared to death because my brother told me I would have my throat slit open."

Larry and Sue Kelly are an odd pair. He is 6'4" tall, thin, gangly, awkward, distractible, fidgety, tends toward loneliness and depression but responds with projects and activity and "keeping on the go." She is 4'10" tall, obese, somewhat lethargic, serious and open in conversation, also tends toward loneliness and depression but responds with eating and sleeping more. Mr. Kelly is quite irresponsible, misplaces his possessions, forgets his schedule, cannot cook, wears the same clothes until his wife makes him change; i.e., he really needs to be taken care of. Mrs. Kelly is domestic and responsible, keeps track of her schedule as well as his with great care, washes his clothes, finds his misplaced things, and claims to like having someone to take care of. It is a family joke that Larry is like another child to Sue.

The two met in high school, married two years after graduation, and shortly thereafter came to eastern Connecticut assigned there by the Navy. Life in the Navy has been difficult for them. Mr. Kelly is a nuclear technician, and whenever

his submarine goes to sea, so does he: stints of anywhere from one week to six months. He has been away at sea more than he has been home. During his daughter's first year of life, he was away 305 days. Mrs. Kelly quickly grew friendly with the other wives, and they have been sources of comfort and activity to each other. The value of these relationships to Sue Kelly is inestimable, but still the weeks and months alone have been at times almost unbearable. The loneliness for Mr. Kelly, sitting for six months underwater at a time, has also been painful. He tries to while away time with little projects, reading novels, playing cards, taking naps. Undoubtedly the men, as their wives at home, were sustaining comforts to each other.

After a year in Connecticut, Sue Kelly had a child. The birth was planned, and the Kellys claim that they had no preference for a boy or a girl. The pregnancy was uncomplicated until the final three weeks. Mrs. Kelly developed severe toxemia with severe hypertension. She was finally hospitalized one week before term, put on a low salt, fluid-restricted diet, and seemed to be losing ground. On the fifth hospital day, she was placed on Pitocin to induce labor. After several hours with no progress, it was decided that the birth canal was too small, and a Caesarian Section was performed. As she and Mr. Kelly were told that any future birth could involve all of the same problems, they

decided that she should have a tubal ligation for sterilization during the Section.

Their daughter, Brenda, was delivered crying and healthy, with a small cleft of the soft palate. Mr. Kelly, waiting outside, was told of the birth and of the cleft. He says that the defect did not bother him: he knew the Navy would pay for its repair, and he had a friend who was born with cleft palate and lip who was now perfectly normal and happy. Mrs. Kelly was told after waking from her anesthesia. She says that her reaction was the same--no alarm, mostly just relief because the birth was all over. Plans were made to have the cleft repaired after Brenda was one year old, when she weighed greater than 20 pounds. There was no history of clefts in either family, so neither parent felt to blame genetically. Mrs. Kelly wonders, though, whether it resulted from her dietary indulgence during pregnancy.

Brenda was an attractive, active seven pound baby when she went home with her parents. But from the start they found her difficult to care for. Immediately, they felt she was willful, stubborn, and difficult to feed. They had to feed her with a Breck feeder (or a "baster," as they told me), and she was forbidden to suck or to put things in her mouth, by doctor's orders. So the feeding process, complicated by spitting up formula from her nose and mouth due to the cleft and by "temper tantrums," was

long and frustrating. And keeping things out of her mouth, especially her thumb, was a full time occupation. They say their doctor recommended binding Brenda's hands with gloves and gauze to keep her thumb from her mouth. They say that at one point he even recommended binding her hands to her sides. They tried it for two hours but gave up because of Brenda's constant crying and dire protest. They would find her asleep with her thumb in her mouth and would take it out. As they told me about these experiences, they clearly were re-experiencing some of the frustrated and angry feelings directed at their daughter. They described how they would withhold a couple meals if she threw a tantrum around one, and that that would help.

At about two months of age, Brenda starting drinking from a cup and was no longer trying as much to suck or to put her thumb in her mouth, and life became correspondingly easier. She grew well for the first four months and had no medical problems. At six months, however, she was growing poorly. It was difficult to interpret her third percentile height and weight, since her mother was of such short stature herself. She has had no other serious medical problems, no hospitalizations.

In her developmental achievements, she has never lagged behind. She rolled over at three months, sat unsupported at four months, pulled herself to standing at seven months, stood unsupported at ten or 11 months, but she fell down the stairs

at 11 months and would not stand again until 12 months. She walked alone at 13 months. At 17 months, she has begun to use words: she says "mama," "lala" (for dada), "no," and "thank you." She imitates speech sounds. She imitates her parents doing household chores and projects. She apparently never went through a period of great clinging to her mother with separation anxiety, and has never been very shy with strangers. She always has "taken to men." She has never been away from her mother overnight, the longest stretches being during the day for eight or nine hours. Her mother feels that Brenda has no problem with these separations.

Mr. and Mrs. Kelly have markedly different relationships to Brenda at this point. Larry and his daughter are pals. She will sit on his lap contentedly, or sit and watch him working on his projects, or play with him with the dog, and squeals with glee when he playfully tosses her up and down. Though he and his daughter are friends, he abdicates to his wife when it comes to the responsibilities of parenthood. "As far as I'm concerned, the baby is for her, not me. As I see it, no matter how much of a pain a kid is, she rounds out a family. She's another person around. Frankly, I don't know what to do with a girl." He claims to have no worries about Brenda's surgery and hospitalization. He figures that she will come through it all right. He is taking a two week leave of absence from work during the

hospitalization but does not plan to visit much. "It would be too hard for the kid to see me come and go, and too far to drive anyhow." He anticipated that the time with his daughter away from home would be a chance "to sleep in in the morning."

Brenda is much more important to Mrs. Kelly, especially since Mr. Kelly has been gone most of the past one and one half years. Sue Kelly sees Brenda as a companion who helps to conquer loneliness while her husband is away as well as a baby who needs her to take care of her basic needs. She takes pride in knowing what Brenda is trying to say and in being able to comfort her. She sounds proud when telling about her daughter's latest achievements or antics. At the same time as feeling very close, and very much in need of and needed by Brenda, she sees her as independent, stubborn, and autonomous; in short, she has some feelings that her daughter could get along fine without her. This is both a distressing and a pleasing quality, as she describes it. She had some concerns about how to relate to Brenda's hospitalization. It has been a question for her whether to room in or not. Her doctor suggests that frequent visiting is unhealthy, as the child will cry more with the comings and goings, and with the crying endanger the suture line in the palate. He recommends either rooming in or very little visiting. It's a complicated issue for Mrs. Kelly. Her

husband clearly wants her to stay at home and visit infrequently, claiming it would be better for both Mrs. Kelly and Brenda to stay away from each other during the time and avoid the pains of coming and going. Mrs. Kelly's father told her over the phone that when she was a young child, her mother stayed with her in the hospital and that she has the same responsibility to Brenda. She feels that it would be terrible for Brenda to not see her parents there, as she has never been away overnight, and that if her husband were away at sea, she would room in. On the other hand, she claims that because of how independent Brenda is, the nurses can provide as good care, physically and psychologically, as she. So the decision not to room in involved conflicting loyalties with her parents, her husband, her doctor, her daughter and within herself.

When asked to participate in our study, the Kellys raised no objections, doubts, or hesitations. They seemed to give a blanket approval for our inquiries, questionnaires, and observations. Mrs. Kelly dealt with us mostly with a serious and openattempt to gain an understanding of what we were interested in and to be of help. She faced our requests with a nonchalant sort of "sure, I don't mind" attitude. This seemed genuine to me, in contrast to Mr. Kelly, who was also accepting and super-hospitable in word, but seemed to have more of a mixed reaction. As he said on

the first interview day, "Sure you come in here and watch. You can bring a whole army if you want, I don't care." Coming from a Navy man, his comment hinted at his feelings that this was a serious intrusion but that he would not protest. His submissive but resentful style of relating to me as an authority seemed throughout our contact with him to be a consistent characteristic.

Perhaps most important of all in understanding what the hospitalization meant to Brenda and her parents is to know what her day to day pattern of experience actually was like at home before: what happened around her, what events and people were part of her life, how she expressed her own particular personality in that context. Then we can better understand which aspects of hospitalization would be the biggest stresses for her and how she might tend to cope with them. In this section, we will therefore describe Brenda, focusing on her activity, her relationship to the inanimate world, her relationship to the people around her, her emotional and expressive life, and her styles of communication. Then we will describe a typical day for her and her mother.

Brenda Kelly is usually moving. Her activity is not filled with zest, but she moves from one involvement, whether person or toy, to another without pause. Although she shows herself capable of persisting at one challenge for quite a long time when encouraged, she usually has a short attention span when sitting with toys. When faced with a task that

demands careful manipulations, she is easily frustrated, somewhat impulsive, and is likely to bang the toy or to throw it aside. She continuously notices new things in the house and is very curious about details; she is an investigator of minutiae: the wall sockets, the thread on the curtain edge, a speck of dirt, a doorknob. In the middle of wandering around the house, she can stop to investigate those interesting things with great patience and well controlled fine motor movements. During her explorations, she constantly checks in with her mother; watching to see where she is, calling to her, letting her know about this or that discovery.

There is tremendous contrast between the neutral times when she plays alone with toys or looks at books, and the very pleasurable and gleeful times when an adult is joining in, encouraging, facilitating, responding. With an adult to watch, she takes great pride in her accomplishments. Otherwise, she seems less colorful. Her favorite times are clearly during close contact with her mother, either when playing with things or just hugging and kissing. At these times she is most expressive facially and most vocal. She loves mealtimes, bathtimes, diaper changes, and these times of physical contact above all else.

Brenda shows little if any shyness with strange adults. She will initiate contact with a sound, gesture, or a tug on the clothes. She freely hugs and kisses an adult she likes,

at her own instigation or in response. She seems to expect adults to respond quickly and comfort her when she falls from a chair, bumps her head, or is stepped on by the dog. At these times, it usually takes physical reassurance to calm her; verbal reassurance won't do.

She demonstrates the ambivalence to her mother expected from a child at this age: she expresses independence, challenges limits, rejects her mother's affection at times. Mrs. Kelly definitely discourages these autonomous, often oppositional qualities, interpreting them almost always as "willfullness," "stubbornness," or "being obnoxious." She responds to them with scolding and brief spankings or by standing Brenda in a corner and telling her to stay there for a few minutes. None of these techniques seem to help, by her report.

Most adults consider Brenda an attractive, active, responsive child "with a lot of personality." Though she is most intimate and expressive with her mother, she is readily affectionate with any adult who is willing to reciprocate. She vocalizes prolifically, babbling to herself as she works, plays, wanders, and she directs words and sounds to her mother and other adults in order to communicate. She rarely gestures to another person without an accompanying "ma" or "la" or a whole stream of syllables. Only her mother

really can read her messages consistently, but given a persistent listener, can usually make herself understood.

A Typical Day

A characteristic of Brenda's typical day is constant closeness with her mother. Up at about 8:00 a.m., she plays quietly, waking up slowly, in her crib for half an hour to an hour. Soon she begins calling out to her mother. Her mother usually responds quickly, coming to change her, bathe her, dress her, and bring her down for breakfast. This whole episode seems pleasurable and intimate for both of them. After helping Brenda with her breakfast, her mother cleans up. Brenda begins her daily work: wandering through the kitchen and living room looking at books, getting her toys out, peering out the window, frequently calling out to her mother, always assured of reasonably appropriate responses. This is a comfortable, active, alert time for her. After Mrs. Kelly cleans up, she typically joins Brenda for a short time in play with toys or books, or hugging and kissing and rolling on the floor. Soon off they go on errands: to the store, the laundry, a neighbor's house, or somewhere else. Brenda likes going out with her mother, always is excited with anticipation as they prepare. Back for lunch, Brenda usually has another diaper change before the meal starts. Thoughout the day, Mrs. Kelly talks to Brenda, sharing her thoughts and feelings, her plans, and her responses to what Brenda is doing. Her daughter

seems to do the same in response. After lunch, mother and daughter are off to their chores again, Mrs. Kelly cleaning the house or ironing and folding clothes, Brenda looking at books, getting a new perspective on the curtains, a table, or a toy, practicing sitting down on a chair, and rehearsing her latest sounds and words. About 3:00 p.m., both go down for naps. Usually Brenda is a little fussy as she gets tired, but she knows when she's tired, when it's nap time; she waves "nite-nite" as her mother takes her up the stairs, and she falls asleep easily and quickly. She wakes up slowly at 4:00 or 5:00. She plays quietly in her crib, babbles to her toys, and eventually calls out to her mother who changes her, dresses her, and brings her downstairs. Brenda's exploratory space is limited usually to the kitchen and living room; her mother puts a gate up at the stairway and has the house doors shut. This is a fairly small space, but actually has quite a variety of things and possible experiences within it. Usually Mrs. Kelly then begins preparing dinner as Brenda plays and explores. Often Brenda imitates her mother doing household chores. She has her own play vacuum cleaner, she has small towels and washrags to fold, and finds pots and pans to put out on the table. Mr. Kelly comes home about 5:30 or 6:00 and often plays with Brenda briefly, tossing her up and down or playing a game of fetch with the dog that Brenda joins in by throwing a ball

to the dog. She usually follows her father around for a while after he gets home, always seeming pleased to see him. All three then sit down to eat. Mr. and Mrs. Kelly talk for a while, sharing their daily experiences, often filled with kidding, teasing, joking, and often argumentative. Brenda usually sits and eats voraciously while watching the two. She occasionally gestures and speaks, usually getting a response from at least one of them. After dinner for two hours, Brenda works at her toys again, but spends more time with her mother and father as they either watch TV or work at their own projects. She gets tired, becoming more cranky and clinging, and finally gets put to bed about 8:00 or 9:00 when she quickly falls asleep.

So this was the Kelly family, as we knew them, as hospitalization approached. The most striking impression to a neophyte observer of families in the home, and this is true also of the observations of the Burns and certainly most families, is the incredibly rich variety of continuous experiences of the infant or toddler with her mother and with her inanimate world. The thought at that time of a hospitalization and separation from home and mother for this child loomed in my expectations as a huge disruption of experience. In a later chapter, when we formulate the problems presented by and resources available for the stress of hospitalization, we shall return to this information. Let us now turn to the Burns family.

Mr. and Mrs. Burns and their 15 month old daughter Gail live in Connecticut in the midst of picturesque rural farming country. Houses and barns are few and far between. The Burns' modest ranch style house, in a large nicely landscaped yard and set at the foot of a wooded hill, has large, spacious, attractive high-ceilinged rooms. The environment is quiet except for cars passing on a nearby highway. The furnishings are appealing and comfortable, and the house is kept clean and neat. The television is usually on, night or day. The Burns are socially isolated, having very few friends or visitors outside their families. The atmosphere in the house is quiet and subdued, dominated by reticence and, at times, argument in the midst of tense marital difficulties.

Robert and Cathy Burns, each 24 years old, moved to this house three years ago when they were married, from their respective family homes nearby. Mr. Burns was born and raised in rural Connecticut with one brother and sister. His parents were never very close as a couple and the family members mostly went their own ways. In the past three years, however, Robert has been together with his younger brother a good deal of the time, helping him to raise horses and manage a new gun shop. He still is distant from his sister and parents. He finished high school, studied for one and a half years in Animal Science at college, then spent six months training in Veterinary Medicine in the Air Force Reserves. Since then, he

has worked at an express company until December of 1974 when he was laid off along with 900 other men. He now receives Unemployment Compensation and spends his daytime between his brother's gun shop, the stables, and his own home.

Mrs. Burns has always been very close with her parents and her one younger sister; she still sees them or talks with them every other day. They "always did everything together as a family." Mrs. Burns finished high school and worked as a Teacher's Aide until she had Gail. She hopes one day to return to that, but for now her day is filled with household chores, gardening, and caring for her daughter and husband. She admits to always having been very nervous and going through times of depression. As a child she took tranquillizers at one point, and again became quite depressed and nervous when she started high school. In each of those times she would almost totally stop eating, feel nauseated, vomit repeatedly, and lose a great deal of weight. In early high school, she even wanted to die, though she had no formal plan for suicide. All of these symptoms have returned in the past few months. When asked if she wants to die, she said "no, I have Gail to take care of." She has never seen a mental health professional.

Bob and Cathy Burns are an attractive young couple. He is a sturdy, well-built man with dark hair, dark brown eyes, a penetrating gaze, and a friendly boyish smile. He impressed me quickly as reticent and as someone whose feelings

are buried deep inside. She is thin with a nice figure, attractive and distinctive facial features, dark brown hair and eyes, and dresses smartly in shirts and pants. She speaks readily of her feelings, and the nervousness that she describes is apparent as she fidgets her hands, strokes her hair, and looks often from place to place as we talk.

The two have had quite different expectations from marriage. Mrs. Burns had hoped to "do everything together," as her parents and family had done. "I wanted someone to talk with and go places with and share everything with. All he wanted was someone to make his food, wash his clothes, pick up his things after him, and to have sex with." She liked him before marriage, "but then it all changed." He started going out more, drinking, spending all his time with his brother. She is jealous of his brother, angry at him for drinking, and tired of "just coexisting in the same house with him." She says she has repeatedly tried to change their relationship, but has always felt pushed away by her husband, who is not unhappy with the marriage as it is. Twice she has separated for a week, going to her parents' house, and as hospitalization approached, she was considering separation again.

After nearly two years of marriage, in March of 1974, Mrs. Burns gave birth in a community hospital to a girl, Gail. Her pregnancy had been both a happy time and a nervous, emotional one. As she recalls, "I had a huge appetite. I could eat anything. I loved it." She claims to have gained 65

pounds, but was healthy throughout the nine months. Labor and delivery went relatively well, but Gail's early life was a catastrophe, due to congenital defects and a mistake made by the obstetrician at birth. Following is a condensation of the records in Yale-New Haven Hospital of her first three months of life.

Gail Burns: Notes on Her 2 Yale-New Haven Hospitalizations

1st Hospitalization: 3/5/74 - 4/1/74

Diagnosis: Omphalocele and severed small bowel.
Cleft Palate.

Operations: 3/6 Small bowel anastamoses.
3/14 Lysis of adhesions.
3/21 Small bowel resection and reanastamosis.

History: 6 lbs. 5 oz. girl born to 23 year old white female at a community hospital in Connecticut at 7:12 p.m. on 3/4/74. APGARS: 9 at one minute, 10 at 5 minutes. Vertex delivery with no complications of pregnancy or delivery. At birth, the obstetrician noted a 1½ to 2½ cm. red projection at the baby's umbilicus. He put a clamp on it and cut it, and sent it to Pathology who examined it. Pathology results: small intestine. Gail fed poorly, spit up, did not vomit. Her abdomen became increasingly distended. The Yale Newborn Special Care Unit was called on 3/5. The intern and 2 others came to the community hospital. On physical examination there, the baby had a distended abdomen and palpable loops of bowel. She was brought in the early evening to Yale-New Haven Hospital. Dr. Touloukian operated that evening, doing a primary bowel reanastamosis. She did not stool for several days postoperatively. She was managed with peripheral hyperalimentation. On the 10th day postoperatively, she began to vomit bilious material. A 3-way film of the abdomen showed air-fluid levels without a perforation. Again she went to the operating room. An obstruction secondary to adhesions was found and lysed. She began to have bowel movements several days after surgery. She was still on peripheral hyperalimentation. Repeat X-rays showed distended loops of bowel with a large amount of gas. She continued to stool. Then she would not tolerate oral feeding for several days. On the 17th hospital day, she was re-explored and her bowel, in the

anastamosis, was found to be abnormal; it was resected and another anastamosis was performed. The postoperative course this time was good, with normal bowel movements and bowel sounds. She was begun on p.o. Lytren which she tolerated well. She was advanced to regular formula. She had a Plastic Surgery consult, and plans were made to operate on her palate between 12 and 18 months of age. She was discharged to home on the 28th hospital day, April 1.

April 11: She came to the clinic and saw Dr. Touloukian for follow up. She was 5 lbs. 12 oz., was gaining weight and thriving. She was on a formula: 4 oz. every two to three hours and tolerating it well. Cereal was to be started after this visit.

2nd Hospitalization: 4/23/74 - 6/8/74.

Diagnosis: Urinary Tract Infection. Starvation and Dehydration. Meningitis. Bilateral Hydroureteronephrosis with Microbladder and Ureteral Ectopia into the Urethra, (i.e., she had large ureters that went directly into her urethra instead of into the bladder).

Operation: 5-8-74, to create Bilateral Cutaneous Pyelostomies (i.e., her ureters were severed from the urethra and brought out to her skin surface on both sides of her lower back, which means that her urine came out the holes to her skin surface).

History: She did well until one week prior to admission. Then she started eating poorly according to her mother. Two days prior to admission, she was irritable, not eating, and had diarrhea. Finally Mrs. Burns brought her to the pediatrician, who sent her immediately to Yale-New Haven Hospital for the second time. She came in with a diagnosis of Starvation and Dehydration. White blood cell count: 43,800. Platelet count: 1,280,000. There was suspicion raised of parental deprivation: as the resident wrote, "clearly they should have realized the severity of the illness sooner." The mother at that time, it was written, just didn't notice how bad it was getting because the dehydration occurred so gradually.

4/24: Meeting with Social Worker. Parents remarkably unemotional. Urinary tract infection with E. Coli developed.

4/26: Meeting with Social Worker: Mother emotional, talked about problems at home with feeding and diarrhea; fought off guilt at having mistreated her daughter. Cells seen in Cerebrospinal Fluid: Meningitis Diagnosed.

4/27: IVP done; no visualization of left kidney.

5/3: Meeting with Social Worker, Dr. Duff (pediatrician), and Dr. Fishaut (pediatric resident): Parents felt better at this meeting. They asked if they were more problematic than other parents, since it seemed to them that they were getting so much attention.

5/7: Diagnosis of hypoplastic bladder.

5/8: Diagnosis changed to bilateral hydroureteronephrosis with a microbladder and ureteral ectopia into the urethra. Operation created bilateral cutaneous pyelostomies.

5/9: Meeting with Social Worker: Mrs. Burns was without husband this time. Became very upset and nearly tearful, but said she could not cry because husband gets very upset. She said that he is becoming more supportive. Parents at this time were discouraged very much about Gail.

6/9: Discharged in good condition.

10/8: Clinic follow-up visit to Dr. Touloukian. Doing well, thriving. 15 lbs., 10 oz.

During this time, as Burns' describe it, they were numb. They did not feel sorrow, pain, or depression as they remember. They did not cry. They came and went to and from the hospital, felt fond of the doctors and nurses, especially in contrast to the ones at the community hospital who they resented for the iatrogenic error. Although they helped in feeding and holding Gail in the hospital, they claim to have felt little affection. They said that Gail did not know who they were and it didn't matter to her whether they were the parents or not.

At three months of age they took Gail home. Mrs. Burns said: "It was like taking a newborn baby home; it could have been any of them." The parents characterized Gail as a newborn as attractive, independent, outgoing, and stubborn. When Gail went home, she had already begun on formula from a bottle and used a pacifier on occasion: both practices were counter to the doctor's orders, but the nurses and parents had decided to do it anyway because it was clear that Gail was much more comforted and secure while sucking.

Ever since she came home in June of 1974, she has grown well, eaten well, slept well, and has had no medical problems. She smiled at two months, crept at four months, walked at seven months, and could kick a ball at ten months. She was never frightened of strangers but has always been a little cautious, since five or six months, and could tell her parents from other people. Her parents report that she seems a little behind in speech. She only says "Mama" though she seems to understand everything that is said to her. The Burns are somewhat worried that Gail, though she seems fine motorically and interpersonally, may be behind mentally and may be retarded. They were told that Gail had meningitis in the hospital and that sometimes that results in mental deficiencies. Because of Gail's problems, the Burns have fears about having another child, thinking more of

adoption sometime soon. Though they see two children as a realistic number in accordance with their financial status, Mrs. Burns "would love to have six or more."

Mrs. Burns has more invested in Gail than does Mr. Burns. She does all of the basic child care, she spends all her time with her, she plays and talks with her, and she looks forward to the future when she can teach her daughter skills the way she did as a Teacher's Aide with other children. She is pleased to have a girl rather than a boy since "girls stay closer to their parents. They call home more often. Boys grow away from their families and usually don't care." She is proud of Gail but she repeatedly has expressed the worry that other people, especially Gail's grandparents, can more adequately care for and comfort her daughter than she can. As the hospitalization approached, Mrs. Burns became increasingly tense about it: "I don't know why; it's nothing like what we went through last time." She fears the pain that Gail will experience, how upset Gail will be afterwards, and worries that she will only make matters worse and that perhaps the nurses will be of more benefit to her daughter than she will. She was given the option of rooming in or visiting infrequently (frequent visiting is assumed by the surgeon to be responsible for more crying and crying for more failures in cleft palate surgery recuperation). When I met her she was undecided, but it took very little

support before she decided to room in, anticipating how difficult for her daughter and herself it would be if she stayed home.

Mr. Burns has never helped much with Gail. He claims he would be more involved with a son. Mrs. Burns feels that "some day Bob will regret that he hasn't gotten closer to his daughter, when she grows up and wants a father to turn to." When he plays with her, he appears still, awkward, unnatural. He hasn't had much practice. As the hospitalization approaches, he says his only worries are financial. "We've been through worse before. It's no big deal." Whereas the Teamsters paid for most of the early costs in Gail's life while Mr. Burns was working for them, he now only has CMS-Blue Cross, which will pay only $30 per day. This will leave them with a bill of $77 per day plus the surgeon's operating and clinic fees. As far as his wife rooming in: "Whatever she wants. It doesn't matter to me. I'll be driving in and out nearly every day with the family to visit."

When asked to participate in our study, the Burns, as the Kelly's, raised no objections or hesitations. They were willing to take part, were pleased that we wanted to create an optimal hospitalization, and were anxious to learn the findings of the Developmental Exam that was part of our study. They showed more interests in our goals and techniques than

the Kellys did, consistent with my judgment that they were somewhat more articulate and psychologically sophisticated.

As when we considered Brenda Kelly, it is most important of all to know what life was like for Gail Burns as she approached the disruptive experience in the hospital. What was her relationship to others like? Her play with toys? How invested in these things was she? What was her emotional life like? How did she respond to stress? What was her language like, how much did she use it? What was her schedule, her typical day? It was this that we were after in observing her minute by minute for so many hours.

Gail Burns, age 15 months, is a zestful child, investing plenty of energy in her activity. She also has her subdued times, while standing or sitting, seeming to ponder and rest. She has a wider variation between zestful and subdued times than Brenda, and has a shorter attention span when exploring her surroundings. She quickly moves from toy to toy and place to place, though with an adult's encouragement, she can stay several minutes at a book or a task. She is not so likely to explore carefully the details of her environment as to just notice everything, perhaps touch or grab or throw, and move on. As she moves about her environment, she frequently checks in with her mother, either by calling out and waiting for a response or by finding her and then leaving her again.

Gail is likely to initiate her own play with her toys: a pull or push toy, her blocks, a book, or one of the family pets. She enjoys having an adult watching her when she plays; she often takes a book or toy to her mother or another adult, requesting either collaboration or just someone to watch her in her accomplishments. She is very pleased with her own successes, does them again and again, and smiles and laughs. She is most expressive and most vivacious during joint play with an adult. Some of her favorite work is in her imitation of her mother, vacuuming, dusting, folding clothes, or just sitting down and standing up again.

Gail is an engaging child. She quickly overcomes her age-appropriate caution to strangers and goes to them, speaks to them, touches, and maybe even offers her hand to them to lead them around the room. Almost all adults consider her a beautiful and appealing child. When she falls or is scratched by the kitten, or meets frustration in her work, she calls out to an adult; if reassured, usually even by voice, she quickly overcomes her setback and is on the move again. If very upset, it needs to be her mother who comforts her, holds her, soothes her. At times she is coy with adults, offering them things and then running away without giving, or backing up until she bumps into someone. When somewhat angry or frightened with someone, she frowns, wrinkles her brow ominously, and calls out "Ma!" A little more fright and she

runs to mother. She challenges limits set by her parents, "obstinately" as they would say, and a typical parental response is a quick spanking. She enjoys the playfulness and physical intimacy around feeding, diaper changes, and baths, though we could not say as we did for Brenda Kelly that these are the greatest joys in her life. Between Gail and her mother before the hospitalization, there was not very much spontaneous hugging and kissing and affectionate play.

Gail is a quiet child. She works, eats, and plays quietly. She does not jabber on and on; she saves her vocalizations, limited to "ma" and "mama," for direct communication and getting what she wants. She is so effective with gestures and the different inflections of her voice, and her mother can read her so accurately, that she needs to say very little.

A Typical Day

Gail, who has always slept in her crib in her parents' bedroom, usually wakes at about 8:00 or 9:00 a.m. and calls out for attention. Her mother quickly responds, gets her out of bed, changes her diapers and her pyelostomy diaper (this is a diaper around her middle to absorb the urine coming from her two ureters which open at the body surface on her lower flanks). She cleans Gail, powders her, and dresses her. Gail is a quick starter in the morning compared to

Brenda. She is up quickly, making rounds from room to room, toy to toy, person to person. Soon she calls out "ma" for food, as her mother prepares fruit and cereal.

Gail is just starting to learn to use a spoon but needs help; she does all right with her fingers. Breakfast is usually quiet, as spoonful after spoonful goes down. After breakfast, down from the high chair, Gail goes about her daily work with her toys and books and pets, always keeping close contact with her mother who is doing the household chores. The dog and kitten are important to Gail, who uses them to express her love, her playfulness, as well as her anger and frustration. The kitten occasionally fights back and the two are a fairly even match.

Lunch, as breakfast, is quick and quiet. After lunch and cleaning up, the two go outside to the yard (in spring and summer). Mrs. Burns works in the garden or flower bed at first while Gail explores the grass and dirt, carrying things around the yard, playing with the cat. Gail loves being outside, apparently because of the distance she is allowed to roam and explore. She takes advantage of every square foot of it. Soon both mother and daughter go to the plastic swimming pool, where Mrs. Burns sits and plays with Gail, who has a magnificent gleeful time splashing, climbing in and out, and dropping everything from the cat to the flowers in the water. This is the most relaxed time of all between Mrs. Burns and Gail.

In mid-afternoon, they return to the house. Mrs. Burns sits in the living room and watches television and works at the ironing or sewing. She wants Gail to take a nap, but Gail usually refuses to and ends up playing near her mother in the living room. After becoming increasingly demanding and fussy, she falls asleep on her mother's lap and is then put to bed for what is usually about an hour nap. Actually this nap is variable in its timing: sometimes in the morning, sometimes afternoon, and sometimes not at all; sometimes 30 minutes and sometimes two hours. In other words, Gail has no particular nap schedule and is, according to her mother, not a good napper.

When Gail wakes, her mother is often preparing dinner, but then comes to get her and change her again. Gail plays by herself, checking in with her mother intermittently. Soon she grows hungry and demands her supper, which her mother is usually prompt to serve in Gail's high chair. When Mr. Burns comes home, he sits and eats with Mrs. Burns, usually very quietly, and this is often a tense time for them. After dinner, the two watch television, visit relatives, or are visited by relatives. Relatives dote on Gail as Mrs. Burns puts it, delighting in her latest achievement or mischievous antic. Rarely does Mr. Burns play with her, though she very much likes him, responds to him, and obeys when he asks her to do or not do something. She goes to bed, often

protestingly, about 8:30 or 9:00 p.m. and sometimes is allowed to cry for as long as half an hour as she falls off to sleep.

So this was the Burns family as hospitalization approached. As mentioned with regard to the Kellys, we will return to this information when we formulate and analyse the hospitalization in terms of likely stresses and available resources to cope with the stress. Our next task is to give you some picture of what the hospital floors were like where these children, and their families to some extent, would be spending a week.

CHAPTER III

THE HOSPITAL WARDS

Although Brenda and Gail entered the same hospital, they entered very different worlds. Brenda was hospitalized on Fitkin 4 and received the usual nursing care there as far as I could determine. Gail was admitted to the Children's Clinical Research Center (CCRC), a small pediatric research unit with an unusually high nurse:patient ratio. It seemed to us more likely that a family could feel secure and comfortable in such a place. In this chapter, I simply wish to describe for you these two different hospital wards, with the particular resources and limitations characteristic of each.

This was not a study designed to compare and contrast two pediatric settings. We hoped to learn from the Fitkin 4 case what the expectable stresses were for a child electively hospitalized for surgery and for her parents. We hoped to use what we learned in our attempt to provide a constructive, non-traumatic hospital experience for another child and family. In the final chapter, we will try to take lessons learned from the second case and consider how they can be applied to routine hospitalizations in general, on typical pediatric wards.

Fitkin 4 is a 25 bed ward serving the pediatric population from zero to four years of age. All rooms come

directly off a long hallway that stretches from the nursing station at one end to the playroom at the other. The Pediatric Intensive Care Unit, off the playroom end of the hall, operates as an entity separate from the rest. Across from the nursing station is one small conference-reading room for doctors and medical students next to a nursing conference room with a staff coffee pot in it. Halfway down the hallway lie a kitchen and bathroom. Off the ward, just around the corner, is a lounge for parents with comfortable chairs, a pay telephone, and a television set. This is an important spot for retreat and mutual support among parents.

The patients' rooms are simple, austere, practical--typical hospital rooms. Each has bed(s), bedside cabinets(s), one or two sinks, and two or three chairs. Brenda spent her eight days in a four-bed room. Parents are allowed to room-in in any room, though if they choose to do it in a four bed room they must sleep on a chair: fire codes prohibit the placement of a cot in a four bed room. Unfortunately for cases such as Brenda, the single rooms are occupied by the most acutely ill children and the children requiring isolation.

The head nurse, for purposes of assigning patients to beds and of assigning nurses to patients, divides the ward into three parts. The rooms closest to the nursing station comprise the Acute section, where patients who need the most

medical attention are admitted. At the middle of the hallway is one four-bed room, the "Nursery," where one nurse at least is always present to care for the youngest of infants. From the middle to the far end of the hall, furthest from the nursing station, is the third and least "acute" section, where children requiring the least medical attention are admitted. This part includes most preoperative and postoperative surgical patients, and is the part where Brenda Kelly was cared for.

Nurses are assigned, in teams, to one of the three groups of beds. This is the Team Assignment system of nursing care mentioned in Chapter III. In addition, individual nurses are frequently rotated from site to site, to avoid the boredom of the least acute section and the tension of the acute section. This, while having these benefits for the nurses, limits the continuity of relationships with a child and family.

The census of patients on Fitkin 4 is widely variable, usually between 20 and 25 but at times dipping below ten. When Brenda was admitted the census was 14; when discharged, about 23.

The staffing hierarchy on Fitkin 4 is the one most commonly seen on large wards of teaching hospitals. At the top, officially in command, is the attending physician, a senior staff doctor who may actually relinquish the major

part of the care to the resident and intern who then use him or her as a consultant. There is one resident in charge of the floor; he or she is available as a consultant to the interns and nurses. The three interns are the real on-the-spot captains. They are each responsible for one third of the patients. Only they know how the patient is doing most of the time, are aware of both the theory and the practicalities of the treatment or diagnostic plan, write the orders, do the invasive medical procedures, and stay in frequent communication with the nurses and parents. One of the interns is available 24 hours per day.

On each shift there is one head nurse, a few Registered Nurses (RNs), a few Licensed Practical Nurses (LPNs), and a few aides. The typical numbers of these per shift are as follows:

	RNs	LPNs	Aides	Nurse:Patient Ratio (assume 20 patients)
Day Shift (7-3)	5	0	0	1:4
Evenings (3-11)	1	2	0	1:7
Nights (11-7)	1	2	0	1:7

The basic weekday schedule on Fitkin 4 is relatively constant; on weekends, when the number of staff members is smaller and few diagnostic and therapeutic procedures are performed, the schedule is much more flexible, the pace is slower, the whole atmosphere is looser and calmer. On all

days, medications are administered regularly, either every four, six or eight hours. Vital signs (temperature, blood pressure, pulse, respirations) are measured and recorded every two, four, or eight hours on most patients. Meals usually come at 8:15 a.m., 11:45 a.m., and 5:00 p.m. Because so many children need help with eating on Fitkin 4, this is a major nursing chore. For efficiency's sake, children old enough to feed themselves are placed in a row of high chairs along the hall. Nurses can continue doing their other duties, going up and down the hall, stopping when they can and when they are needed to help out. If a child's parents are there, this of course makes the eating potentially a more personal experience for the child and less of a burden for the nurse.

We can arbitrarily say that the day begins with the night shift to day shift nursing report between 7:00 a.m. and 7:30 a.m. The house staff report begins at 8:00 and walking rounds are made by house staff and students, room to room, between 8:00 and 9:00. For the children, the hours between 7:30 and 10:00 are times of eating, medical procedures by the interns, and diaper changes, bed changes, bathing, dressing, as well as medications and vital signs by the nursing staff. It is a very busy time on the floor. Play time is scheduled from 10:00 a.m. to 12:00 noon. Available and willing children, and their parents if present, go to the

playroom with the Child Life Worker and volunteers. It is usually a time of pleasure for the children, with lots of individual attention in looking at books, playing with toys, listening to records and making music, using clay, splashing water, and so on. Interns perform procedures, schedule children for various tests, and evaluate test results. Often during this time, children must leave their play to accommodate the scheduling. During the afternoon and evening the busy nursing schedule continues, with cleaning, bathing, changing beds and diapers, giving medications, taking vital signs, and regulating IVs. In addition, there are usually admissions to take care of. More parents are around, and can be seen with their children in their rooms, pacing the halls with their children, or sitting in the playroom. Children without parents present wander the hallway if they can; or play in the playroom; or remain in their hospital cribs amusing themselves, crying, or sleeping between the times the nurse comes to perform her scheduled duties; or are carried around by nurses who are doing their chores. The evenings are somewhat quieter than the daytimes. Fewer doctors are present and fewer procedures are done. More parents and visitors are with the children, and families stay in the rooms until 8:00 p.m. unless they are rooming in. During the night, as the children sleep, nurses checking IVs, vital signs, and giving medications punctuate the dark and quiet hours.

So, Fitkin 4 is large, noisy, busy, staffed with a fairly clearcut hierarchy of people each of whom knows what he/she has to do. The nursing staff seems always to have more than enough to do. They walk quickly all the time, up and down the hallways, except when they are with patients or are taking a break in the conference room. Efficiency and time-saving methods carry a high premium. With such large numbers of purely procedural things to do on so many patients, individual and relaxed attention to a child and family often must carry a low priority. The extent to which it happens will depend on several factors: how easy it is to meet a child's needs while still doing chores is one important one. While observing Brenda Kelly, a conversation I had with the father of another child highlighted how this works. He had noticed that another child in the room, a toddler who was not confined to bed, seemed to receive lots of attention from the nurses in the form of playing and walking and talking with him; this in contrast to Brenda Kelly, confined to bed, who only saw nurses at times of procedures of some kind. He suggested that this seemed to be because the child could accompany the nurses on their chores and because he was a demanding persistent child. Another important variable in how a child's needs are met is of course whether or not a parent is present. In such a busy, seemingly hectic place, the parents can act as

comforters, as protectors, as mediators for their child. This I can illustrate with an example involving the same father with whom I had the conversation above. His son was to have surgery. As the family was from India, the child spoke both Indian and English, and at three years old, was difficult to understand. When he was crying and wanted to wipe his eyes, he cried out "nims," which to him meant "napkin." When the attendant came to take the child to surgery, his father told the attendant that everyone who would be with his child after surgery should know the meaning of "nims." The attendant promised to pass the message on, but the father, suspicious, wrote a note and pinned it to the bed. We will see later that the absence of this crucial mediating role in a hospital, interpreting and providing for the very young child's needs, can be devastating for the child.

The physical layout of Fitkin 4, as with any structured setting, facilitates some kinds and discourages other kinds of interactions. For a nurse, to be out in the hallways means to be working; even if she has no chore she is focusing on at the moment, she is likely to be called by a doctor, a child, or a parent or family member. To rest, the nurse goes to the nursing conference room, has coffee, a cigarette, or just a rest. This room seems to be for nurses only, not parents, not doctors, occasionally infants

(with the nurse). Doctors similarly have their room next to the nursing room; this room is used occasionally also for a family conference. Children of course have their playroom and bedroom. The playroom is only visited by doctors and nurses to find a child for a scheduled test or procedure, medications or vital signs. The playroom is not a comfortable place for parents. The parents' "retreat" is off the ward, as mentioned before. This is not a casual meeting place for any staff people. So we can see that staff-parent interactions other than admission, discussion of medical findings or studies, casual conversation during procedures on children, and discharge are discouraged by the use of the space around the ward as well as by the staff's busy schedule. In addition, a pleasant warm atmosphere where parents can be with their children is lacking on Fitkin 4 as it is presently structured and used. This can have really far reaching ramifications, as the parents of many children, ambivalent already about being in the hospital with their children, are less likely to feel welcome in such an environment.

The Children's Clinical Research Center (CCRC) is a small, eight bed research unit accepting children of all ages who are approved as subjects in research projects. The ward lies beyond a set of double doors on Fitkin 3. Four one-bed rooms, one four-bed room, a nurse-doctor-family conference room, and a kitchen all come directly off a large

central space that includes the nursing station and a parent-child TV-play room that serves as a parent-nurse lounge as well. A parent lounge is present outside the double doors, but is rarely used.

Each room is simple and austere, similar to those on Fitkin 4, with beds, sinks, cabinets, and chairs. The children needing the most attention are put in the single rooms closest to the nursing station, but due to the cluster arrangement of rooms around the center, this only means one or two steps closer. Cots for parents to room in can be placed next to any bed; when a family chooses, a cot can be placed for each parent. Rooming in on the CCRC is strongly encouraged. For one thing, the meals for one parent are provided gratis, as well as one long-distance phone call per day, this even for children not receiving the benefits of a research grant.*

The patient census on the floor varies from one to eight. During my week of observations and Gail's stay, there were always either two, three, or four patients. This meant that Gail could be given very specialized attention.

Staffing on the CCRC does not involve the same typical hierarchy spoken of on Fitkin 4. There is no intern. The

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*Most CCRC patients are covered by a research grant. This covers hospital fees, tests, medications, food, phone calls. Gail Burns, however, was placed by the Board of the CCRC into a different category, meaning that her parents and Third Party Payers had full hospital fees to pay, or $107 per day.

resident, whose chief responsibilities are out beyond the double doors on Fitkin 3, is also responsible for some of the duties in the CCRC and is available for nurses' questions and requests. The real doctors here are the attending physicians whose patients are part of their own research projects in most cases. They come in daily, often several times, write orders, speak with nurses and families, and do many of the procedures themselves. On this floor, the real on the spot captain is the head nurse, who can freely and does freely call on the attendings and resident. Because of this relationship and due to the special interest in these patients, the nurses in general are more aware of the diagnoses and treatment plans than is common on other floors. They sit in on conferences with the doctors, and the head nurse frequently duplicates articles for them to read about the current patients' problems and treatments.

On each eight hour shift, there is one head nurse, and others as follows:

		RNs	LPNs	Aides	Nurse:Patient Ratio (assume 5 patients)
Day Shift	(7-3)	4	1	0	1:1
Evenings	(3-11)	1	1(?)	0	2:5
Nights	(11-7)	1	1(?)	0	2:5

Because the patient census is so small, the ages of the children so varied, and the parents of most small children room in and assume major responsibility around the caretaking

of the child, the hallmarks of the daily schedule are individualization, flexibility, and variety. The basic outlines are similar to those on Fitkin 4. Medications are given as ordered, usually every four, six, or eight hours. Vital signs are measured and recorded as ordered, usually every two, four, or eight hours. Meals come at 8:15 a.m., 11:45 a.m., and 5:00 p.m. But there is no particular time for visits from the doctor that would correspond to "rounds" on Fitkin 4, no particular playtime, though the children on Fitkin 3 can go to playtime on Fitkin 4 and Fitkin 5 (for 2 to 12 year olds) if they so wish, and no particular time when procedures are done. When the children play, or rest, or have procedures and tests done with them revolves highly around the child's and parent's schedule, as would be true around the house. It was obvious while observing on the CCRC that needs to have diapers changed, needs for affection and nourishment, and interests in playing and interacting are impossible to respond to appropriately on a schedule; they are needs best responded to on the spot; which means that someone who knows the very young child very well must be paying close attention in order to read his/her messages. And this is the philosophy guiding the staff on the CCRC in relation to very young children.

The atmosphere on the CCRC is that of a small, warm, supportive "community," a term used several times by nurses

and parents in response to questions I asked about the setting. As one parent said, "It's funny. It doesn't even seem like a hospital." I asked what she meant. "Well, it's not sterile or cold. The people here have time for you, take an interest. You feel like you belong here." The distinction between work and rest, or between meeting physical versus psychological needs of a child and family are blurred in this setting: parents are doing "nursing chores," nurses obviously regard the parents and some children as people to relax with, people to respond to as human beings. With a relatively small proportion of their time fully occupied with basic medical and caretaking tasks, the nurses seem more relaxed.

The use of the space of the CCRC goes further to solidify bonds between nurses and parents and children. The conference room with the coffee pot is for all people, including the doctors. It is very common to see nurses and parents sharing this space, having a casual talk. The TV-play room as well is used by all. It is comfortable for relaxing, for television, for the kids to play in.

The end result of the staffing, the layout, the flexible scheduling and the philosophy is that the children and parents on the CCRC feel that they belong there, that their questions get answered, that they know one and probably several nurses quite well, and that they have a supportive network of people with them during a time that can be emotionally

difficult. This is certainly how Mrs. Burns felt during her hospitalization, as we shall see in a later chapter.

Our considerations in this chapter have admittedly neglected many relevant factors in the environment and in the staff that influence the care of a given child. We have not touched on intra-staff relationships; on what happens to staff members when they are having difficult feelings in relation to a child or parents, or the whole group of children and parents, or the administration of the ward or hospital. There is fertile ground for sociological investigation of hospital wards; for instance, see Duff and Hollingshead's Sickness and Society. But that was not our focus. We have tried here to give you a good idea of what the wards were like in brief, so that you can better picture the families and their experiences as we now go on to describe the hospitalizations in detail.

CHAPTER IV

THE FIRST HOSPITALIZATION

During Brenda Kelly's hospitalization on Fitkin 4, I played the role of a non-participant observer. Sitting usually 10 to 20 feet from the bed, I continuously recorded what I saw for several hours every day, minute by minute, varying my time schedule to include morning, afternoon, evening, and overnight hours. I watched parents, nurses, doctors, students, and technicians come and go from Brenda's bedside. To them, I became a silent, immobile fixture in the corner.

Behind the calm, unobtrusive observer stance required for detailed documentation, I was very disturbed by what I saw. Again and again I suppressed natural urges to protect or to comfort Brenda, or to inform someone who could be of help to her when she needed it. I more and more questioned the ethicality of what I was doing and reexamined my own motives. Almost daily I discussed the troubling things I was seeing with my co-investigator, Dr. Ferholt. At times I found myself wanting to dismiss what I saw with a "So what? She'll get over it!" but the reality remained.

The account of what I saw, presented in this chapter, was difficult to write. I wanted to avoid being misunderstood. I wanted neither to present an exaggerated picture of Brenda's suffering nor underplay the traumatic aspects.

After two complete rewritings of the account, I finally resolved to just tell the story as I saw it unfold, omitting all editorial comment, liberally quoting from the observations I recorded at the time, selecting portions that were characteristic of the untold parts of the story.

As an overview of the course of events during the hospitalization, I present here the treatment plan and orders of the surgeon, Dr. Mombello:

<u>Preoperative Orders</u>

1. Admission one day prior to surgery (on a Sunday).
2. Preliminary laboratory procedures, including drawing of blood.
3. Evaluation that evening by an anesthesiologist to clear Brenda Kelly for surgery (ascertaining that no infection was present).
4. No food or drink after midnight the first night.
5. Antibiotics (Penicillin) preoperatively, and postoperatively for 10 days.

<u>Operative Schedule</u>

1. Premedication at 6:00 a.m. (on Monday).
2. Taken to operating room at about 7:15 a.m.
3. Surgery to begin about 8:00 a.m., lasting 1½ to 3 hours.
4. Parents to be called by surgeon at their home immediately following surgery.

<u>Postoperative Orders</u>

1. In recovery room, where parents cannot visit, for 2 to 3 hours after surgery.
2. I.V. in for 24 to 48 hours after surgery; for fluids, for antibiotics in case she refused oral administration, and in case of transfusion.
3. Clear liquids to be begun the first day after surgery.
4. Strained fruits allowed beginning the fifth postoperative day.
5. No milk or milk products for two weeks.
6. Sedation (Phenobarbitol) to be given as necessary to prevent crying.
7. Tylenol by rectal suppository as needed for pain relief.

8. Watch for fresh bleeding from mouth. If even one drop seen, call Resident and Surgeon immediately. Look at actual wound as little as necessary.
9. Inside croupette (mist tent) for one day.
10. Elbow restraints, from fingers to shoulders, on for six weeks. Removable under close adult supervision, only one at a given time, for passive exercise.
11. Restricted to room the first two postoperative days. On third day, out on ward in stroller.
12. From fourth day onwards, increase activity as desired, but still minimize crying.

Two weeks prior to admission, Mrs. Kelly took Brenda to see Dr. Mombello. At that time he explained to her in detail: the reason for and timing of the surgery, the schedule of the postoperative procedures and restrictions, and how Brenda would look and act directly following surgery. He told Mrs. Kelly that she had the option of (1) living in with Brenda in the hospital for at least the first four or five days, or (2) visiting not too frequently during that time period. He thought that too many visits would result in Brenda's crying too much, endangering the suture line in her palate before it had a sufficient chance to strengthen. He told her that soon she would be receiving a telephone call from the hospital admitting office, providing her details about when to arrive and what to bring.

Several days prior to admission, Mrs. Kelly received a call from the admitting office. She was told to come on Sunday, about noontime, and to bring Brenda's clothes and a couple of her toys if she wished. This was the sole prehospitalization contact between the family and the hospital. The

family and the staff would meet as strangers, and the first impressions and interactions would naturally be very important.

As discussed in Chapter II , Mrs. Kelly was conflicted about whether to room in. Her loyalties were divided between her daughter, who she knew would be frightened and lonely, and her husband, who wanted her to stay at home with him. Her father had told her that she had a responsibility of rooming in, but she was under the erroneous impression that it would cost the price of another bed, $107.00 per day. She did not know the nature of the accommodations for parents on Fitkin 4 and was not familiar with anyone who had been there. Because of the importance for Brenda of whether she roomed in or not, and because the Kellys seemed reluctant to face the issue, I asked what their plans were several days before hospitalization. Mrs. Kelly seemed hesitantly resigned to staying home with her husband, with plans to visit daily if possible. She feared that the nurses were going to be more competent in caring for Brenda than she was, and had no sense as yet of what her caregiving role would be. She grew increasingly tense as the day of admission approached. It seemed at that time fortunate that they were being admitted on a Sunday and when the census was only 14 patients. The floor was usually least busy on Sundays, and with a low census the staff should be more available.

Larry, Sue, and Brenda Kelly arrived in the admitting office in the calm of a Sunday afternoon. Brenda was excited

by the new place, exploring every nook and cranny. The parents were tense, quiet, anxious to do the right things, go the right places, and to keep Brenda nearby. An admissions clerk met with them and filled out a sheet with family demographic data and inquired about plans for financing the hospitalization. He asked if Mrs. Kelly would be rooming in. She looked at her husband, who looked the other way, and she said, no, she guessed she wouldn't be. After a series of admission procedures and laboratory tests, the three were sent to Fitkin 4. They met the Intern and Resident, neither of whom expected the admission. "Are you sure they didn't say Fitkin 3? We had no idea you were coming." There ensued a few minutes of confusion, more questioning of the Kellys, and finally a call to Admitting who assured them that the Kellys did belong there.

They were sent to a four bed room; no other patients were in it. They sat quietly for 25 minutes. A nurse came in and asked questions as she filled out her admitting sheet. She weighed Brenda and took her temperature, pulse, and blood pressure. Brenda was hesitant, kept checking with her mother before and during each procedure. She was taken to the hall with the nurse in order to find a doctor, and she burst out crying immediately. She was returned to Mrs. Kelly and just as quickly stopped crying. With her mother's presence, she could tolerate the strange place, strange people, and

intrusive procedures--just barely. An hour passed; no one came to the room. Mr. and Mrs. Kelly wondered whether they should leave or stay. Having had no orientation to the schedule or tour of the ward, they seemed too shy, or unsure, or perhaps intimidated to just venture into the hall and ask someone.

Finally the Resident came, asked questions, did a physical exam, and took Brenda down the hallway in his arms to draw blood from her. She screamed and cried throughout the procedure, and when returned to her mother this time could not be calmed. She was still upset when the intern came, asked questions, quickly did a physical exam, and left. After the Intern left, I asked the parents how they felt. They said they were confused about what to do, and felt unwelcome since they arrived, were not sure which persons were doctors or nurses or students, and wondered if they ought to leave. Mr. Kelly wanted to leave; Mrs. Kelly wanted to leave only if she knew there was nothing she could do to help her daughter. Although individual personnel were friendly enough, the parents never felt they got to know anyone, that day or during the hospitalization.

Throughout the encounters with the admitting nurse, the Resident, and the Intern, no one mentioned anything about the parents' living in or visiting. The issue was raised again as the Kellys sat quietly in Brenda's room on the day of admission:

> Mr. and Mrs. Kelly sit quietly. Mr. Kelly reads an information sheet that his wife found at the nursing station. Mrs. Kelly points out to him the section stating that rooming in is possible, that a cot could be provided. He makes his position on the matter clear again: 'It won't do Brenda any good and it will make you a nervous wreck.'

That was the final mention of rooming in that day. It was never discussed with a Fitkin 4 staff member.

Brenda, though subject to exams and procedures, still seemed relatively secure as long as the parents were there that first day. At 7:00 p.m., after a dinner and playtime were shared by Brenda and her parents, she was put to bed. The side rails were raised to confine her, her parents quickly said goodby and left. She was alone in the room, excepting the unresponsive observer in the far corner. She cried loudly in protest for a few minutes, standing and holding the rails. Soon she stopped, she lay down on her side staring at the door, and finally fell asleep seven minutes after she was left. She was awakened later for her first dose of Penicillin. She cried for several minutes, and was then comforted into silence by a nurse. She scanned the room persistently, remained surprisingly quiet and inactive, and fell to sleep in the nurse's arms. She slept well that night.

Surgery itself, and the immediate few hours afterwards, were very upsetting for Brenda and her parents. Mrs. Kelly's tension, according to her friend, as well as by her

own report, reached its peak the day of surgery. Brenda was sedated early in the morning and at 7:45 a.m. was in the operating room. Three hours later she woke up in the recovery room, surrounded by several sleeping strangers and three busy, unfamiliar nurses. They provided competent, efficient care of her mist tent, her mouth, and her I.V., but had little time to soothe her. She sat inside a transparent tent with mist blowing into it, had rigid arm restraints from shoulders to fingers on both arms, and blood and saliva were oozing from her mouth packed with gauze. She showed no interest in anything or anybody in particular; she just cried monotonously for two hours. At that time, 12:45 p.m., she was returned to her room on Fitkin 4.

Mr. and Mrs. Kelly had been told by Dr. Mombello to remain at home until he called them postoperatively. He called, telling them the surgery went smoothly, and that they could now come in to visit. He reminded them how she would look--mist tent, arm restraints, IV, bloody mouth, cranky and unhappy--and what restrictions would be placed on her--no liquids until the next day, strained fruits in five days, no activity for three days. The Kellys arrived at the hospital at 11:30 a.m. and spent 1½ hours roaming the hallways and visiting the cafeteria while Brenda was in the recovery room. At 1:00 they went to see Brenda in her room.

Brenda is on her stomach, IV in right arm, both arms wrapped and splinted. She lies in a spread eagle position. Mr. Kelly goes to her, looks at her, their eyes meet. In about 15 seconds, she stirs a bit, tries to get up. Her mother comes to help her, picks her up. Brenda does not make eye contact with her, looks past her, does not reach for her or hug her, is acting very passive. This continues for three minutes as she holds Brenda and tries to comfort her. Mrs. Kelly sits down holding Brenda, and finally Brenda whimpers a bit. In three more minutes she is crying vigorously, but not hugging her mother, or looking at her, or responding to her physically. Mrs. Kelly makes efforts to comfort her, but Brenda arches her back and acts rejecting. During this, her father calls out to her once. She looks at him, cries louder, and he says, 'I guess I just don't rate.'

Nurse takes Brenda back. In between times the nurse had been out of the room busy with other chores. Mrs. Kelly watches the nurse's every move, seeming to be hovering between wanting to do something for Brenda and wanting to leave. The nurse immediately puts Brenda on her belly in bed, explaining to Mr. and Mrs. Kelly that Brenda will be most comfortable this way. Then she ties and pins down Brenda's two arms and both ankles. Brenda lies still, crying. Mrs. Kelly watches on, closely. She looks at the IV bottle, watches it drip, seems to be examining it. She comments to the nurse that Brenda has a fever (she had felt her forehead). The nurse makes no response. (Four minutes pass) The nurse finishes, has also put a mist tent back over Brenda and turned it on. Mrs. Kelly moves into Brenda's line of sight and speaks to her. Brenda cries louder and turns her head the other way, looking at the mist machine. Her mother stays there, though, looking at Brenda. She speaks to the nurse: 'I guess there's nothing I can do now. I suppose we should just go home.' No response, as nurse cleans up. 'Will she just be lying like this for the next 24 hours? I feel so helpless now. What can I do?' Nurse: 'She has to lie like this so she doesn't get too rambunctious.' Father asks nurse, 'What did they do to Brenda?' Mrs. Kelly rephrases the question diplomatically: 'How was the cleft palate repaired?' The nurse doesn't

> know how. Mrs. Kelly comments to Mr. Kelly, 'After all this, she may never be willing to go to the babysitter's again.' In conversation with the nurse again, Mrs. Kelly asks what Brenda can eat, when she can eat. The nurse explains that she can have fluids tomorrow, but no milk since it coats and interferes with the sutures. The nurse explains that Brenda will be sedated for some time, to keep her from crying. Brenda has settled down by now, seems to be sleeping. Mrs. Kelly looks at Brenda and says, 'If I could do something for her, I'd want to stay here. I feel so helpless.' Nurse leaves room. Parents sit down.

By asking the head nurse, I discovered that the reason why Brenda was tied by all fours to her bed was to prevent her from pulling out her I.V. For the next 15 minutes, Brenda was quiet; her mother sat in a chair and watched her. Only the parents and Brenda (and the observer) were in the room.

> Mrs. Kelly gets up, goes over to Brenda. Brenda looks at her, starts crying, turns her head the other way. Nurse returns. Mrs. Kelly tells her: 'She has a bloody discharge from her nose.' Nurse checks her, wipes her face, starts untying and unpinning her arms and legs, in order to get a urine specimen. Mrs. Kelly comes close to the nurse, trying to get involved; she talks with the nurse about how hard it was to get a urine specimen yesterday. The nurse turns Brenda over in bed. Brenda protests and cries fiercely. Mrs. Kelly asks, 'Should I get you another diaper?' Nurse accepts the diaper, starts to put a plastic bag on Brenda to catch her urine. The nurse decides this time to pin Brenda so that she is lying on her side. Mrs. Kelly comments to the nurse that Brenda likes lying on her stomach better. The nurse continues, however. Mrs. Kelly tries to comfort Brenda as she gets tied down. She cries louder. Finally she is all pinned down, forced to look in the direction of people, away from the mist machine that she had been looking

> at. She kicks, moves around. Nurse tries to tie her down more firmly. At this point, the nurse asks me, 'Is this the first child you have observed?' I answer, 'The first one I've really watched in detail.' Nurse leaves. Mrs. Kelly repeats twice more that she wishes there were something she could do. 'I guess we should just go home when she goes to sleep.' (Five minutes pass)
>
> Brenda is still struggling and crying. Mrs. Kelly looks on as she struggles, then looks out the window, seeming a little exhausted. She goes to Brenda's bed and says 'nite nite' but gets no response from her daughter. Mr. Kelly says to her, 'Give up?' She walks to the window and looks out, tears in her eyes.

Throughout this difficult time for Brenda and her mother, Mr. Kelly adopted a very cool, detached, "business as usual" sort of attitude. He read the newspaper and occasionally suggested to his wife that they really ought to leave. It was only an hour later though, that he answered Dr. Ferholt's question of how the hospital was treating his daughter with, "If they treated Brenda like this anywhere but the hospital, I would strangle them."

Just a few minutes after the passage quoted above,

> Nurse returns, tells Mrs. Kelly that they will give Brenda more Phenobarbitol and put her back on her stomach. Mrs. Kelly: 'I know she'll be happier on her stomach.' Nurse unpins her again. Brenda cries and kicks in distress. (Three minutes pass) Brenda is pinned down on her stomach again. The nurse tells Mrs. Kelly that she could pat and rub her daughter, maybe that would help. Mrs. Kelly rubs and pats Brenda's bottom. Her daughter faces her and quiets down. She slowly falls asleep. Mrs. Kelly stays and looks at her, fidgets with the mist tent. She says to the nurse, 'I guess we should go. There's nothing more that I can do for her.' Nurse: 'I think it should

> be up to you whether you go or stay. You can hold her when she wakes up if you want to.'
> Mrs. Kelly: 'I just want to take her home.'

Ten minutes later, Mr. and Mrs. Kelly went home, planning to return the next day. I spoke with them before they left. They told me it was upsetting not having Brenda home last night. They kept thinking she was in her room, or in the back seat of the car when they drove. Mrs. Kelly didn't get much sleep: "I kept hearing Brenda crying." They were very curious about how she slept that first night in the hospital.

That evening and night, Brenda remained strapped to her bed almost all of the time. She was kept on maximum doses of Phenobarbitol, but still cried most of the time, according to the nurse. The nurse assumed that the crying was due to the painful bloody mouth; she came in often to clean it out, to pat her and talk to her, and to get her up for short times in a carriage. Nothing seemed to help.

1st Postoperative Day

Brenda's mother and a neighborhood friend visited for three hours, from 12:00 noon until 3:00 p.m. When they arrived, Brenda was under the mist tent, all fours bound to the bed, lying face up. Mrs. Kelly: "I would strangle any babysitter who did that to her, but it's for her own good." For two hours, Mrs. Kelly was allowed to hold her daughter, who alternated between sleeping and sobbing drowsily. Mrs. Kelly seemed to be much more comfortable

than yesterday, as she played more of a role in Brenda's care. I quote here from segments of the hour from 2:00 to 3:00 before Mrs. Kelly and her friend left.

> 2:00. Nurse (different from yesterday) comes to put Brenda back in bed. She wakes her, and Brenda starts crying. Mrs. Kelly and her friend watch on. Nurse starts to pin Brenda down again, face down this time, when the surgery Resident enters and wants to listen to the patient's chest. Brenda protests violently, kicking, crying, coughing. The doctor tells the nurse that Brenda needs changing. The mother watches on as the nurse changes the diapers and takes a rectal temperature. Brenda is still upset, crying. When the nurse leaves for a brief period of time, she stops crying.
>
> 2:10. Dr. returns, removes IV. Mrs. Kelly and her friend are clearly very relieved. Brenda watches its removal, is interested, has stopped crying. Nurse watches also. Doctor: 'Make the Phenobarbitol more frequent; she is supposed to be resting more.' Mrs. Kelly: 'Do you need to make her quieter?' Doctor: 'She is pretty resistant to our therapy.' Doctor leaves, nurse remains, holding Brenda's arm with a gauze pad where the IV was, preventing the bleeding. Brenda is sobbing quietly. Nurse leaves. Mrs. Kelly stays with Brenda, holding the gauze pad now. She pats Brenda's bottom, which soothes her daughter.
>
> 2:23. Nurse comes to give Brenda her medications (via syringe placed into back of mouth, necessarily by force). Then she gives Brenda to her mother, who holds her, seems very pleased to be able to comfort her. Brenda quiets down, is calmer, watches the door for more nurses. Mrs. Kelly rocks in the chair as she holds her, and Brenda begins to weep. Her mother lays her on the bed on her belly, patting her bottom. Brenda quiets down, seems more comfortable like this. Nurse comes, tells Mrs. Kelly that Brenda needn't be strapped down any more, that the elbow restraints are now her only physical restrictions. Brenda is looking at her right hand and moving it around; it has been immobilized up until now with the IV. Brenda looks at her mother,

> vocalizes to her. (First vocalization from Brenda, a usually jabbery child, since surgery, as far as I know.) She lies listlessly in bed looks tired, her mother pats her. Brenda looks at her mother, who is talking quietly to her.
>
> 2:40. Brenda is very calm now. She is looking all around: at me, at Mrs. Kelly's friend, the other beds in the room. She is jabbering the way she did before hospitalization.
>
> 2:48. Brenda is getting more playful with her mother. She smiles as she plays with some toys. She turns herself over in her bed, rolling around with pleasure. Mrs. Kelly puts up the bed rail, tells Brenda to go 'nite nite.' Brenda lies on her belly, looks up again and again at her mother, tries to find a good comfortable position. She gets up again, stands in bed, hits on the bed rails. Her mother comes and Brenda smiles at her. Mrs. Kelly puts her down again, tells her to go to sleep. She quiets down, her mother and friend leave to go down the hall for a minute. Brenda goes to sleep.

Mrs. Kelly and her friend came back and since Brenda was asleep, they left, planning to come back in two days.

That evening, Brenda was very calm when awake, though she was asleep during almost four of the five hours while I observed (6:30 - 11:30). I recorded the following when she was awake.

> 8:26. Nurse wakes up Brenda to give her the medications (Phenobarbitol and Penicillin). She protests and fights, but soon the procedure is finished. Nurse picks her up for about five seconds, lets her down again. Brenda stays awake in bed, playing with a stuffed poodle from the hospital (her parents brought no toys); she watches other children who now occupy the other beds.
>
> 8:53. Still doing the same thing, never making a sound.

> 9:00. Brenda still awake, lethargic, fiddling with her hands. Another boy in the room is noisy, crying.
>
> 9:25. Brenda is still lying quietly awake, looking around.
>
> 9:40. She finally falls asleep.

She was perhaps better sedated that evening. She lay so quietly awake for so long before going to sleep. I wondered what she was thinking at the time, and how she had come to such apparent peace with the situation.

2nd Postoperative Day

On the second postoperative day, Brenda no longer had the IV, was not tied down, was not in the mist tent, and was beginning to take fluids. Her mother did not come to visit, she still had her arm restraints, and she was still under maximum sedation. She was cared for by two nurses during the day, one of whom had been her nurse two days before, and the other of whom was new to her. With other patients now in her room, she received somewhat more attention and social stimulation in general.

She woke at 9:00 after having a good night of sleeping, according to the night nurse. The next hour was unpleasant, as I recorded:

> 9:05. Brenda is awake, lying in bed, looking around. No one comes to her. She looks sleepy, dazed, is quiet. She soon starts sobbing, which she does off and on.
>
> 9:30. Nurse comes with medications. For three minutes, with Brenda crying and kicking and struggling, the medications are forced down her mouth as she is held on her back in bed.

> 9:33. The one syringeful of medication finished (one to go), nurse leaves as Brenda is crying.
>
> 9:36. Nurse returns with another syringe, this time with the other medication. Brenda protests less this time. She likes the taste of this medication. This takes two minutes, then the nurse leaves again. Brenda continues to cry for one minute. Then she quiets and watches as another patient in the room is rolled away (to go to surgery). Her mouth, which due to the arm restraints she cannot wipe, is messy with drool and medication.
>
> 10:10. She has been alone now for half an hour. For the past ten minutes she has cried periodically. Now she is crying vigorously.

At that time another nurse came to attend to her, bathe her, dress her, feed her jello. They spent an hour together, the nurse devoting comfort and affection to Brenda. Accordingly, she became more and more playful and responsive. For instance, at 10:25, I recorded:

> Brenda is in her bed for a bath. Nurse takes elbow cuffs off. Brenda is not crying anymore. She watches the nurse closely as she bathes her, powders her, and dresses her. Brenda is quite cooperative, seems pleased to have the attention. It seems that she has given this nurse the right to take care of her and to receive the reward of caring for a responsive baby. She gets more interested in things around her, more than almost anytime since surgery.

During the afternoon, there were three main things that made Brenda happy. One was the chance to go out in the hallway. Unfortunately, she was still heavily sedated, and walked clumsily, unable to stand without being held. The second thing was when she received a long period of close supportive attention. The times in the afternoon, however,

were usually brief, though frequent. When she was left alone for more than a few minutes, she cried and was unable to really invest herself in anything else. The third thing that pleased her was the chance to drink. She was fed jello and apple juice, and drank both voraciously. The apple juice, however, was for her an intolerable food, as her mother had explained to the admitting nurse. It caused her to develop diarrhea within a short time. As she was fed apple juice throughout the hospitalization, her diarrhea remained until she was taken home.

I was not in the hospital to observe that night. Unfortunately, the nursing notes provided no clue of how the night went for her; only that she was awakened at 6:00 a.m. for vital signs. Brenda's daytime nurses the next day did not know how she had slept either. In talking with the night nurse the next time she came on duty, I found that Brenda had been awake crying on and off, but that the nurse wasn't sure just how much, altogether, since it had been a busy night.

3rd Postoperative Day

> 8:30 a.m. I arrive just as Dr. Mombello does for his morning rounds. Brenda is sitting in her bed, crying, looking at us as we enter. Her face is red from crying, her eyes are tearing, her mouth is drooling. Her crying is moaning, persistent. The parents of another patient tell me that she has been crying for at least 15 minutes before, which is when they arrived, and that no staff member has attended to her. Dr. Mombello looks through the bars and talks to Brenda. This does not comfort her. Her diapers are very obviously soiled.

8:40. Brenda continues to sit and cry.

8:50. Crying continues, without any moving about. She continues to look at the door as she cries. The mother of the other patient reaches through the rails and strokes Brenda's head. She is quite upset by Brenda's distress and wonders aloud why Brenda's mother doesn't visit more. A nurse comes in to check on the other patient but does not look at Brenda. As the nurse leaves, Brenda flops around in the bed, on her back and her front, then sits up again; her cry is now more varied in intensity and demanding in tone.

8:55. Same nurse enters room again, but again it is for the other child. Brenda looks at her and cries louder. There are two toys in the bed, put there two days ago, but Brenda is not using them.

9:00. The doctors and medical students and head nurse are on rounds. They come in, going to the other patient's bed. There are nine of them. Brenda sits crying, looking at them, but not one turns to see her. As they leave the room, one calls out, "Goodbye, Brenda."

9:05. The same scene continues. Brenda is flopping all over the bed, her crying now consists more of pulses of loud, desperate crying with a quieter weeping in between. As she cries, tears are no longer coming from her eyes.

9:10. I go out for two minutes, return. She is still crying, flopping around, hitting herself against the rails. The nurses all seem to be busy working with other patients on the floor.

9:15. Brenda's crying continues. It is now more like bursts of screaming with silence in between. She crawls around in her bed, stands on her head and feet, rolls forward from that position onto her head.

9:21. Brenda is rolling back and forth, lying on her back, crying, tugging on her soiled diapers. A nurse comes in, comments to Brenda that her diapers are dirty. She gets a wash rag and puts down the bed rail. Brenda reaches her arms to the nurse, wanting to be held. The nurse puts her immediately on her back, saying 'Wait until I get

your diapers changed.' Brenda continues to cry. The diapers changed, the nurse now picks her up and carries her out to the hall. Brenda is crying less but still weeping as the nurse stands with her in the hall.

9:35 Brenda has been put in a high chair along the side of the hall. She is alone, and reaches out to the passersby as they move up and down the hallway.

9:40. She is interested in the people walking by, and in some little styrofoam bits on her high chair. Another child stands next to her chair, and Brenda watches him. She has stopped crying, and seems to be more pleased to be out in the busy hallway of human activity.

9:43. She is restless in her high chair, struggles to get out. She can't quite do it. She keeps trying, but gets quickly frustrated and bangs her head on the back of her chair. She looks at the table next to her, spots some food just out of reach. She tries for it, and when she can't quite get it, starts to whine. A nurse comes by, as does the ward secretary. They get the other child, make no contact with Brenda.

9:47. Fidgeting, whining, restless in her chair.

9:49. Trying to climb out of the chair, whining, reaching for food again; at one point she nearly falls out of her chair.

9:50. Cries get louder. People continue to pass by. She still reacts to each person as a possible hope, someone to stop.

9:58. Brenda's nurse comes by, opens a box of cereal for her. Brenda spills it, the nurse cleans it up, then leaves. Brenda plays with the wrapping paper. She tears the cellophane to shreds; she offers pieces of it to people passing by.

10:03. A different nurse walks by, stops for a couple of seconds to say hello. Brenda continues to tear up the cellophane, distracted by everything around her.

> 10:09. A different nurse than has cared for Brenda at all yet stops, sits down with Brenda with a cup of apple juice. Brenda drinks it all down quickly.

That nurse took Brenda back to bed and cleaned her up and bathed her. What was most remarkable was the very affectionate way in which Brenda responded to this completely new person. For the next two hours, whenever a nurse did something nice, Brenda was very responsive, and whenever she was the slightest bit rejected or abandoned, she immediately cried in great protest.

During the afternoon, Mrs. Kelly and her friend came to visit and stayed for five hours. It was a painful time for her, as her daughter rejected her throughout the visit. Here is an excerpt from my observations:

> Mrs. Kelly takes her down the hall and back for a walk. But if she tries to pick her up and comfort her, or hug her, Brenda doesn't allow it. She arches her back, uses her arms to push her mother away. Mrs. Kelly is clearly uncomfortable, feeling rejected, unable to do anything right as far as Brenda is concerned. Mother puts her on her belly on the bed, patting her bottom, hoping that that old comforter will do the trick as it always has at home. But it doesn't; Brenda only acts angrier. Mrs. Kelly puts her on her lap and pats her bottom again. Same response; Brenda will have nothing to do with her mother, never even makes eye contact with her, tries to walk away from her.

A few minutes later Mrs. Kelly and her friend were talking about why Brenda was so upset. They considered it a combination of diaper rash, sore mouth, teething, arm restraints, and diarrhea from the apple juice. Conspicuously lacking was the acknowledgement that it was only with Mrs. Kelly and

not with the nurses that Brenda was acting so rejecting. It must have been upsetting for Mrs. Kelly to have the head nurse tell her that day,

> She is the best little eater. We bring her a cup and she drinks it right down. And she really likes people.

During the final hour of the visit, Brenda did start to respond to her mother, started to play with her, smile at her, babble to her. It seemed like a sudden change. She then was quite satisfied with her mother except for even the slightest frustration, which sent her into angry, crying, rejecting behavior again.

In the late afternoon, Mrs. Kelly left her daughter again, and Brenda cried as she walked down the hall. I spoke with Mrs. Kelly. She said it was very hard to leave because she knew it made Brenda cry. She felt guilty about not being there. She said she was nervous at home, had headaches, and when she came to visit found that she couldn't do anything to help her daughter. She was in conflict with her husband at home more than usual and couldn't wait until Brenda returned home. She said that she planned to visit two days later, on Saturday, and Dr. Mombello told her Brenda would be discharged on Sunday.

4th Postoperative Day

Brenda slept most of the morning, was awake from 10:50 until 11:30, then slept again until 1:45 p.m. The reason she woke up at 10:50 was as follows:

> Technician comes in to get blood by sticking Brenda's toe. Brenda still lies mostly asleep. She gets stuck, starts crying, does not fight or move her legs, just passively cries about it. After a couple of minutes she does start struggling, kicking. Technician leaves. . .

Shortly after the technician left, a familiar nurse came in, approaching Brenda affectionately just to play with her and pick her up. However,

> Nothing will satisfy Brenda. She fusses, cries, hits each toy that is offered. She does not want to be held, or put on the floor, or put in bed. This goes on continuously as the nurse and I talk. After 25 minutes, nurse puts Brenda in bed. Brenda fusses and cries and the nurse pats her bottom the way her mother does. By 35 minutes after she first came in, Brenda starts to quiet down, and soon is asleep.

As usual, the middle of the afternoon was a busy time for the nurses. Brenda was awake at 1:45 p.m. She started crying, and continued unabated for three continuous hours without receiving any response from an adult. In fact, no nurse came to the room during that three hour period. My observation period ended at that point and I left, the scene unchanged.

5th Postoperative Day

This was a Saturday when the patient census was high. Therefore, a weekend staff, smaller than weekdays, would be unable to provide very much individual attention, even less so than on weekdays. This made the day difficult for Brenda, whose mother did not come to visit as she had planned. I

observed Brenda crying from 12:00 noon until 1;30 p.m. During that time, she had a one minute visit from the Plastic Surgery Resident, who said she was doing well medically, and a 30 second visit from a nurse at 1:00 just to see how Brenda was doing. She had more acutely needy patients up the hallway.

> 1:30 p.m. Brenda is very hungry, but fussy and particular about the food the nurse now feeds her. The nurse takes her in her arms as she looks for a shirt for Brenda. Brenda is complaining but quite accepting of being held.
>
> 1:42. Nurse leaves, 12 minutes after coming. Brenda returns to her earlier state, sitting and crying steadily.

She fell asleep after another 10 minutes. She slept until 2:30 when she was awakened for her medications.

> The nurse has to force the medications down Brenda, who struggles and cries. She speaks to Brenda briefly and leaves. Brenda lies awake, quietly, in the bed.
>
> 2:36. Brenda still awake, becoming more fussy.
>
> 2:41. Brenda takes off arm cuff by herself. She plays with it, looks through it, tries to put her foot through it.
>
> 2:43. She becomes more frustrated, cries. She is both crying and playing with the cuff.
>
> 2:45. Throws cuff on floor, lies on back, cries helplessly. Kicks, rolls around.
>
> 2:50. Same.
>
> 3:05. Still crying, unattended by a nurse. I see her sucking her thumb and make a rare intervention myself to put the arm restraint back on.

> 3:25. Brenda is still crying, now more intensely than before, tossing a stuffed animal around angrily. She picks at her clothes and diapers, and throws a blanket on the floor.
>
> 3:30. Nurse comes to Brenda: 'Still awake. My goodness, when will you take a nap. You are tired.' Nurse lets down rail, Brenda reaches for her. The nurse picks her up. Brenda quiets briefly, then starts crying again. The nurse puts her in the playpen in the hallway but this doesn't please her either. 'You don't want to be in the playpen, you don't want to be in bed, you don't want to be in my arms. What can I do? You are so tired.'

I was not there to observe during the evening or night.

6th Postoperative Day

This was the intended day of discharge. But because the Resident did not remove Brenda's palatal packing on Saturday when that was planned, it had to be removed on Sunday and discharge put off until Monday, the 7th postoperative day. Mrs. Kelly was called in the morning and told. When I talked to her later over the phone, she was quite angry. She said she would not even be coming in to visit "since we will be coming in tomorrow anyway. That's why we didn't come in yesterday; we thought we would be coming in today. I'm coming in tomorrow and taking her home no matter what." She continued to inform me that she was depressed and nervous and was "just waiting" for Brenda. She was angry at the hospital, not only for the unexpected postponement, but also because Brenda was repeatedly fed apple juice against Mrs. Kelly's warnings and because Brenda's diapers were not changed often enough.

Most of that day Brenda slept. She was still maximally sedated, and the Phenobarbitol seemed to be working better now. When awakened for a meal at 1:00 p.m., Brenda was quite passive and accepting as the nurse cleaned her face, changed her diapers, and dressed her. She was neither crying nor pleased. The nurse wanted to feed her, but was too busy to do it by herself. She placed Brenda in a high chair in the hall.

> Nurse has to leave for a phone call. Brenda has no food yet. She watches the passersby, interested in them. She reaches for things around her, all just out of reach. She becomes more uncomfortable, starts crying. (Three minutes pass) A different nurse notices Brenda, asks me who is feeding her; I answer by telling her who put her there. She goes off down the hallway. Brenda cries more. It is a cry that stops immediately when someone comes to her. (Five minutes pass) Brenda continues to cry; her nurse is very busy with other patients up and down the hall. A third nurse stops, talks to Brenda for 40 seconds, but this doesn't help. Her original nurse returns, Brenda stops crying, seeming to recognize her. She speaks to Brenda, but has to leave again. Brenda cries louder, throws a piece of paper on the floor. (Two minutes pass) Brenda's original nurse sits down with her, feeds her pear sauce. She can't seem to get the bites in fast enough. Nurse talks with another nurse as she feeds her. Other nurse leaves, now Brenda's nurse is talking to her as she feeds her. Brenda refuses a cup of apple juice.

For the next 40 minutes, Brenda was fed as the nurse found time, in intervals. She was then put in her bed and dropped immediately to sleep. She slept for two hours, until my observation period ended.

Day of Discharge

The parents arrived at mid-morning and seemed to be in quite a hurry to take Brenda home.

> They are both saying how great it is to be getting her out, how difficult it has been at home, how nervous Mrs. Kelly has been. Brenda is neither pleased nor displeased, is acting indifferent to everyone, is just passively going along with the rush.

Within 15 minutes the Kellys were on their way out, had to stop in a laboratory to have blood drawn once more. Dr. Ferholt administered a developmental evaluation, and finally they left.

Follow Up

One day following discharge, I visited and observed in the Kelly's home.

> They invite me in. They are sitting on the bed and I on a chair. They are clearly very relaxed today and very friendly. They tell me about how Brenda has done since coming home yesterday morning. She has more temper tantrums than usual, she woke up more during the night and had more trouble going to sleep than usual. She won't drink from a cup the way she did before. She throws everything given to her over her shoulder. She laughed at the dog once, briefly, but other than that she has not laughed or smiled, has just been 'ornery.' Mr. and Mrs. Kelly say they are mad at the hospital and nursing care for two reasons: (1) they were told she would be discharged on Sunday and it happened on Monday instead; and (2) the nurses persisted in feeding Brenda apple sauce and apple juice after the Kellys had told them Brenda couldn't tolerate it--she got diarrhea as a result and now still has a diaper rash because she sat too long too often in soiled diapers. Brenda is still on Phenobarbitol three times per day.

Five days following discharge I visited the home again. The Kellys explained that Brenda was acting somewhat better, but that the sleep disturbance persisted.

> Mrs. Kelly tells me that Brenda has, since she was discharged, taken no morning naps, which she always took one of. She only is taking an afternoon nap. She is going to sleep later at night and waking up crying earlier in the morning. So she is receiving considerably less sleep, is tired and cranky more of the time. Mr. Kelly tells me that she has been consistently "cantankerous" at meals, a time which for her always used to be a pleasant one.

My observations that day revealed Brenda to be in quite good spirits, pleasant with her parents and well invested in toys. This was just following a nap, however, and the parents explained that it was only when she started to get tired that she was upsetting; when well rested, she was just like she used to be.

Nine days following discharge, Mrs. Kelly seemed tired and tense.

> She says Brenda is getting better, is back to her old self again in her mood and her eating habits. But not in her sleeping habits. She still is going to bed about two hours later than she used to, getting up earlier, getting tired as the day goes on, taking only one nap, leaving out the morning nap she has always taken. She is by now off all medication.

On that day I also spoke with Mrs. Kelly's neighborhood friend:

> She has known the Kellys for two and one years. She talked with Mrs. Kelly nearly every day during the hospitalization. She says that Mrs. Kelly was unusually nervous during that time, the most on the day before and the day of surgery. Then she

> was a bit relieved. Mrs. Kelly really only relaxed once Brenda was home again. I asked what it was that seemed most upsetting for Mrs. Kelly. She said it was that Brenda was pinned down, crying, and she was unable to help her. She said that now Mrs. Kelly is back to normal, but that Brenda is still upset, especially in her sleeping habits and her irritability from lack of sleep.

Twenty-four days following discharge, I talked with Mrs. Kelly on the phone, She said that Brenda was very well, except that the same sleeping problem continued.

Nursing Interviews

Within one day of discharge, I interviewed five nurses, each of whom had cared for Brenda at some point during her hospitalization. First I asked them about her characterisistics and about their own relationships with her. There was unanimous agreement that (1) Brenda was an affectionate, responsive child who was easy to care for; (2) it was easy to know when she needed attention because she cried immediately; (3) she coped quite well in the hospital and was not very upset by the experience; (4) the only times when she seemed to be upset were directly following surgery and then when her mother came to visit her. There was general agreement that, due to heavy sedation, it was difficult to know what Brenda was usually like.

Two nurses had gathered the impression that Mrs. Kelly was retarded, and one thought Brenda might be. No nurse came to feel very familiar with Mrs. Kelly. One nurse of the five considered her to be helpful in Brenda's hospital care; two

felt that she was mostly in the way, always hovering and wanting to be involved. No one knew what was most difficult for the parents about the hospitalization. There was general agreement that Mrs. Kelly was concerned but not very upset at any point.

The final question I asked was for an idea of what an "ideal" hospitalization would be like. Opinions varied greatly. One nurse thought that rooming-in would be helpful in children over the age of two; her experience indicated that when children were under two, it was more difficult to care for both mother and child than for the child alone. One nurse suggested: (1) units for parents to room in, including kitchens and other facilities; (2) provision of the same nurse every day for a child, one per shift, with extensive information passed on at change of shifts; and (3) extensive parent interviewing to be done at admission. She felt that due to the physical layout and staffing patterns, rooming in and continuous case assignment nursing for a child would be very unlikely to happen on Fitkin 4.

One Registered Nurse, who had more experience on Fitkin 4 than most others, spoke about the staffing patterns on the floor. In the nursing assignments, no priority was given to continuous nurse-child relationships except when a nurse requested to stay with a child. "Always at least one nurse will like a child." Nurses alternate between working at one end of the floor and the other. She said that because nurses just work five days per week, "the continuity of a

nurse-child relationship couldn't be kept up anyway." She said that no child passed through the ward "without getting a good dose of TLC."

Developmental Evaluation

Brenda had three developmental evaluations, as performed by Dr. Ferholt: one on the day of admission, one on the day of discharge, and one a week following discharge. The quantitative results were as follows: (see the particular items on the Yale Revised Developmental Schedule in Appendix, Part 2).

Expected Skills at 18 months	Prehosp.	Discharge	1 Week Later
Motor Skills (6 items)	5 of 6	0 of 6	6 of 6
Adaptive Skills (6 items)	3 of 6	0 of 6	5 of 6
Language Skills (6 items)	0 of 6	2 of 6	2 of 6
Personal-Social (3 items)	0 of 3	0 of 3	2 of 3

The discharge scores reflect her acutely upset state directly following hospitalization. During the testing session, she first sat in her mother's lap. Dr. Ferholt offered her a ring toy; she tossed it toward her father. She did the same with two consecutive red blocks, and again with another ring toy. Her mother suggested that maybe she was thirsty. Dr. Ferholt offered a cup of ginger ale, which

Brenda pushed away. She refused everything offered. In the meantime, Mr. Kelly had a toy gun in his hand, aimed it at Brenda and pulled the trigger several times. Brenda was put on her feet to walk. She just fell and squirmed on the floor and refused to be picked up. Her father shot her several more times. The exam came to an end.

The gains one week later were striking. As well as improving her quantitative scores as shown in the table, she impressed Dr. Ferholt as being happier, more verbal, less impulsive, more thoughtful, more careful in problem solving, and more curious about the items offered to her. The observations included that Mrs. Kelly seemed considerably more relaxed than during previous evaluations. So, at least as we can tell by our testing and observations, although Brenda was more tired and irritable and having trouble sleeping, her level of developmental achievement did not regress during hospitalization and in fact, even seemed to have improved.

Child Behavior Questionnaire

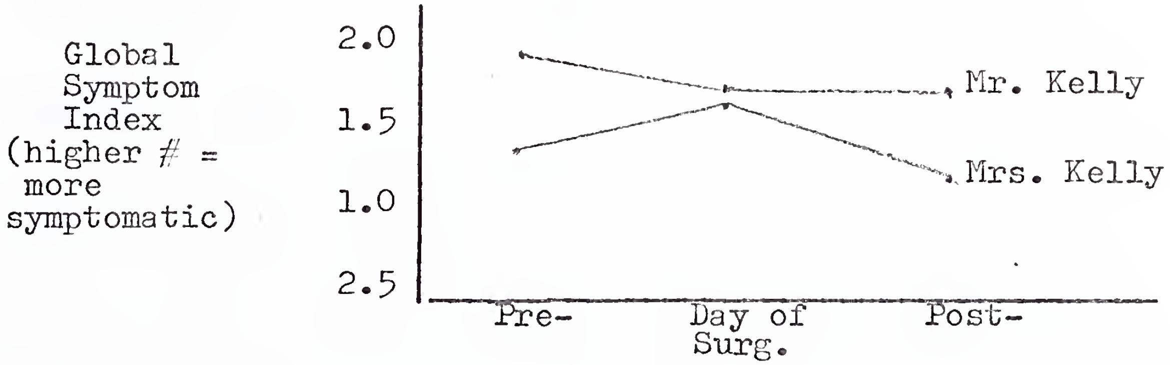
The changes in this questionnaire between the prehospitalization and posthospitalization periods demonstrated what was also discovered in parent interviews, by direct observation, and in developmental evaluations. Brenda seemed, in her parents' estimate, to have returned to normal in most behaviors, with evidence of slightly more independence. Only

in the questions related to sleep patterns was a disturbance reflected.

SCL-90 Questionnaire
(See Appendix, Part 2, for explanation of scoring.)

Global Symptom Index:

	Prehosp.	Day of Surg.	Posthosp.
Mr. Kelly	1.9	1.7	1.7
Mrs. Kelly	1.3	1.6	1.2



Factorial Symptom Indices:

Factors	Prehosp.	Day of Surg.	Posthosp.
Somatization			
Mr. Kelly	1.5	1.1	1.3
Mrs. Kelly	1.5	2.0	1.0
Obsessive-Compulsive			
Mr. Kelly	2.7	2.7	2.3
Mrs. Kelly	1.5	1.6	1.1
Interpersonal Sensitivity			
Mr. Kelly	1.4	1.4	1.6
Mrs. Kelly	1.4	1.2	1.2
Depression			
Mr. Kelly	2.3	1.7	1.9
Mrs. Kelly	1.3	1.4	1.2
Anxiety			
Mr. Kelly	2.2	1.8	1.7
Mrs. Kelly	2.1	2.3	1.1

Factors	Prehosp.	Day of Surg.	Posthosp.
Anger-Hostility			
Mr. Kelly	2.0	1.8	2.0
Mrs. Kelly	1.3	1.3	1.3
Phobic Anxiety			
Mr. Kelly	1.0	1.0	1.0
Mrs. Kelly	1.0	1.0	1.0
Paranoid Ideation			
Mr. Kelly	1.8	2.0	1.5
Mrs. Kelly	1.7	1.3	1.2
Psychoticism			
Mr. Kelly	1.7	1.9	1.6
Mrs. Kelly	1.3	1.0	1.0

Individual Items

As can be seen above, Mrs. Kelly followed the same general pattern in almost every factor as she did in her global score of symptomatology: i.e., she was most symptomatic on the day of surgery, had been slightly less so prior to hospitalization, and was markedly least symptomatic following hospitalization. The particular factors that followed this pattern most strikingly were Somatization (1.5, 2.0, 1.0), Obsessive-Compulsive (1.5, 1.6, 1.1), and Anxiety (2.1, 2.3, 1.1). The particular items in which she showed the same pattern most markedly were Headaches (2,4,1 on a scale of 5), Worry too much (3,5,2), Nervous or shaky inside (4,5,1), Tense or keyed up (3,3,1), Feeling so restless you can't sit still (2,4,1), poor appetite (1,3,1).

Mr. Kelly's picture was much less consistent. Some factors showed less symptomatology during hospitalization than either before or after: Somatization (1.5, 1.1, 1.3),

Depression (2.3, 1.7, 1.9), and Anger-Hostility (2.1, 1.8, 2.0). Some of the particular symptoms that were exacerbated for Mr. Kelly when his daughter had come home were: Feeling blocked in getting things done (4,2,4), Unwanted thoughts that won't leave your mind (3,1,2), Low in energy or slowed down (4,1,3), Nervous or shaky inside (2,1,4), and poor appetite (1,1,4). However, his picture did show more symptomatology during Brenda's hospitalization in the more severely disturbed factors: Paranoid Ideation (1.8, 2.0, 1.5) and Psychoticism (1.7, 1.9, 1.6).

Summary of SCL-90:

In general, the findings of the SCL-90 support our direct observations and interviews with the parents. First of all, Mrs. Kelly, nervous prior to hospitalization, became most severely distressed during hospitalization, especially the day of surgery, and following hospitalization became much more relaxed and confident. Mr. Kelly, much less attached to his daughter and a more high strung, symptomatic person altogether, in some ways was relieved by his daughter's absence from home; he was less nervous and more energetic. The findings demonstrate an important dynamic in this family which contributed to Mrs. Kelly's choice not to room in. This is the tendency for Mrs. Kelly to be the caregiver in the family, for both her husband and her daughter, who both need her very much, but for the husband to have the last word when at home.

Discussion

After observing Brenda Kelly's experience in the hospital, we tried to specify just what the most stressful aspects were for her. We used this analysis to prepare an overall treatment plan for Gail Burns' hospitalization (see next chapter). What follows is a discussion of each stressful factor.

1. Prehospitalization Anxiety.

This affected Mrs. Kelly most strongly. Brenda was unaware of the coming hospitalization, though she may have sensed her mother's anxiety, which was fueled by several concerns, including:

a. Mrs. Kelly's conflict about rooming in;

b. Her fear that the nurses could care for her daughter more effective than she;

c. Her unfamiliarity with the hospital environment--its routines, its accommodations, and the role that she could play within it;

d. Her fear that Brenda may be damaged or killed by surgery. This remained unspoken, but accounts for her intensely heightened anxiety the day of surgery, and her relief shortly after the operation.

It seemed that, in large part, this stress occurred because of the absence of any preadmission contact in which Mrs. Kelly could learn about the hospital ward and her possible role in it. It may also have helped her to work out her conflicts about rooming in and to air some of her fears and anxieties,

freeing her up to care for her daughter rather than protect herself.

2. Admission, Strange Place, Unknown Adults, Change in Routine.

These were the stresses of entering a new and intimidating environment. Mr. and Mrs. Kelly felt unwelcomed, unoriented to the ward and its schedule, and unsure of the part they should play. This remained stressful for Mrs. Kelly throughout the hospitalization, as she never felt familiar with any staff members and never grew comfortable on the ward. She became angry at the nursing staff for (1) feeding her daughter apple juice against her advice and (2) not changing Brenda's diapers when they were soiled. As a result, Brenda developed diarrhea and an extensive diaper rash.

For Brenda, this factor was most important when her mother was gone, as no one replaced Mrs. Kelly in mediating the harsh unpredictable realities of the new environment. The Team Assignment Nursing System, with a superimposed rotation of nurses from team to team (see Chapter III) presented her with new caregivers throughout her stay and prevented a continuous nurse-child relationship for longer than two consecutive days at the longest. The times when she was fed, comforted, played with, or when her diapers were changed were not generally the times when she wanted or needed them. Her schedule, well suited to her home environment in which it was formed, was disregarded; a foreign one, suited

to the busy nursing care system, was imposed on her. Sometimes she cried and sat in soiled diapers for more than an hour without a response. When she was "mothered," it was usually around procedures and was done hurriedly and efficiently.

3. Separation of Brenda from her Mother.

Mrs. Kelly visited only three times in eight days. At home, she felt guilty for leaving her daughter, angry at the hospital staff for mistreating her daughter and providing her no role to play, and angry at her daughter for causing the trouble in the first place. She grew depressed and nervous, had headaches and other somatic complaints, as she was "just waiting" for Brenda to come home. Her anger at Brenda, and intimidation by the hospital resulted in her not visiting after the third postoperative day.

For Brenda, separation meant (1) abandonment by her "primary object" as well as (2) direct exposure, unbuffered by a protecting, comforting adult, to the demands, intrusions, and confinements of the new place. She rejected her mother in anger during the visits, while she was gradually accepting more comforting by the unfamiliar nurses. Considering the pervasive depriving effects on Brenda and the damage to the mother-child relationship, it would be worth going to great lengths to prevent separation or to provide adequate replacement for an absent mother.

4. Procedures.

Procedures such as blood drawing and administration of medications were predictable, regular occasions of stress for Brenda. Regardless of the approach, she panicked and protested. But different styles of approach seemed very much to affect her ability to regain her equilibrium afterwards. Procedures were most distressing (1) when they were performed hurriedly, without friendly contact beforehand, and (2) when no time following the procedure was allowed for comforting and soothing Brenda.

5. Surgery and the Immediate Postoperative Period.

This seemed to be the most traumatic time for Brenda and her mother. Brenda woke in a strange room amidst unfamiliar people, inside a mist-filled tent. She was sedated, had a painful bloody packed mouth, arm restraints, and an I.V. Her parents were not in sight. After two miserable hours, she was brought to Fitkin 4 and there, before her parents, was pinned by all fours to her bed. Her mother hovered anxiously over the nurses as they did the "mothering" care. Mrs. Kelly later reported that the worst time for her was this helpless period when her daughter was strapped down before her.

6. Sedation.

Brenda was sedated at maximum doses throughout most of her hospital stay. It was ordered to prevent her from

crying. But it had only a limited effect: while she probably did cry less than if she weren't sedated, she cried tiredly and monotonously most of the time she was awake. In addition, sedation carried with it serious side effects that rendered Brenda less capable of employing her own resources to cope with stress. It blurred her perceptions, undoubtedly confused her thinking, and made her actions clumsy and maladaptive.

7. Restriction of Motion.

Brenda was to wear rigid arm restraints, preventing her elbows from bending, for six weeks postoperatively. This was to keep her fingers out of her mouth. She was to be kept inactive in her room for at least three days, the first two of which she was to remain in bed. For the first 24 hours, she was strapped by all fours to her bed in order to prevent her from pulling out her I.V. She sometimes struggled desperately against constraints for more than an hour--to stand, to get through the side rails, to climb out of a high chair, or to remove her arm restraints.

As was the case with sedation, the restrictions, while ordered for particular purposes, carried with them incapacitating side effects. An entire system of aggressive discharge was blocked. Due to the restrictions in combination with the sedation, primitive global movements expressing frustration and anger usually predominated over more advanced and adaptive motor activities.

In the next chapter, we will present our attempts to apply lessons learned here about stresses. In the final chapter we will further explore the implications of Brenda Kelly's experiences.

CHAPTER V

THE SECOND HOSPITALIZATION

This was an unusual research project for the Children's Clinical Research Center. Usually patients are only admitted with highly interesting diseases; the disease and the patient occupy center stage. In this case, the research was a study of the hospital child care process itself, with doctors, nurses, patient, family, and myself all on center stage. And although I initiated the project, it was designed, performed, and evaluated by all participants. It was a unique and significant historical event. I will here be reporting on this concentrated undertaking to help a child and her parents have the most constructive, therapeutic hospital experience possible.

I was ready for it. I had studied the literature on children's hospitalizations. I had watched the Kellys for a week in the hospital without intervening. I had been reading about care of cleft palate children and families. Pages and pages of notes and plans pointing toward Gail Burns' hospitalization had accumulated and I felt tired of just watching and reading. I thought I had something to offer.

The surgeon, Dr. Mombello, and the Burns family had agreed to the project. When I first met with the Research Unit nurses, I found them also ready and enthusiastic. It presented a challenge for them, a case where the focus would be on the components of excellent nursing care. We only had two more weeks to prepare, and during that time wanted to meet with the surgeon and perhaps with the family in formulating an overall treatment plan. Meetings came almost daily.

Dr. Mombello, whom I knew from the Kelly's hospitalization, was enough intrigued by the proposal to be in support of it. He was willing to use the CCRC rather than Fitkin 4 and he looked forward to a meeting with the nurses.

He came to the CCRC Conference Room one week prior to admission at 12:00 noon. The table was spread with cold cuts, lettuce, mustard, and pie. Dr. Mombello was offered a cup of coffee and we all sat at the table as he stood at the blackboard and began. He drew diagrams as he classified cleft lip and palate disorders, discussed the methods and appropriate timing of the repairs, and finally went into the preoperative, operative, and postoperative nursing care and family counseling. He was obviously pleased with the special lunch occasion and the attention with which he was listened to, and he proved in return to be friendly and flexible in how his nursing orders could be met. The meeting was a success in terms of information transmitted and an alliance begun.

The surgeon's orders, identical to those in the first case, were as follows:

Preoperative

1. Admission one day prior to surgery.
2. Preliminary laboratory procedures, including drawing of blood.
3. Evaluation that evening by an anesthesiologist to clear Gail for surgery (ascertaining that no cold or infection was present).
4. No food or drink after midnight that first night.
5. Antibiotics preop and postop, for ten days.

Operative

1. Premedication at 6:00 a.m.
2. Taken to the operating room at about 7:15 a.m.
3. Surgery beginning about 8:00 a.m. and lasting from 1½ to 3 hours.
4. Parents to be called by surgeon immediately following surgery.

Postoperative

1. In recovery room, where parents cannot visit, for 2 to 3 hours after surgery.
2. I.V. in for 24-48 hours after surgery; for fluids, for antibiotics in case she refused them by mouth, and in case of transfusion.
3. Clear liquids to be begun the first day after surgery.
4. Strained fruits allowed beginning the fifth day postop.
5. No milk or milk products for two weeks.
6. Benadryl or Phenobarbitol to be given as necessary for sedation. Sedation indicated in order to minimize crying, which could put pressure on suture line.
7. Tylenol by rectal suppository as needed for pain-relief.
8. Watch for fresh bleeding from wound. If even one drop seen, call the resident and surgeon immediately.
9. Look at the wound as little as necessary.
10. In croupette (mist tent) for one day.
11. Elbow restraints on for 6 weeks. May be removed, only one at a given time, with close adult supervision to keep her hands from her mouth.

12. Restricted to her room for first two days. On third day, out on ward in stroller if there is no fear of infection from other patients.
13. From the fourth day onwards, increase activity if Gail wants to, but still trying to minimize her crying.

Adequate performance of these did not represent the goals of a truly therapeutic hospitalization. They were our ground rules, our "givens," our limits. It was what we did in addition to this outline, and the manner in which the specific orders were carried out that would make the difference we were looking for. The child and parents as individuals whose lives were disrupted and stressed, needed as much careful attention given toward their support and recuperation as the painful palate was to receive.

We developed our overall treatment plan over the two weeks prior to admission. It reflected several inputs. First of all, it was a problem-oriented approach in which the detailed orders directly followed from a formulation of the anticipated stresses. These were the stresses discussed in the literature review and in the previous chapter. Secondly, the plan reflected careful consideration of the strengths and vulnerabilities of the particular individuals involved, as formulated in Chapter II. This aspect naturally required prehospitalization contact with the family. Thirdly, the plan reflected the input from the nursing staff, who had had the most experience with the problems faced and who were most familiar with the resources available in the hospital and

on the ward. This required close collaboration among the nurses, the surgeon, and myself. Finally, the plan included the "givens" from the surgeon, the pre and postoperative care as outlined above.

I present the plan here completely organized according to the stresses we anticipated and how we planned to meet them. In the actual process of developing and implementing the plan, it was never quite in this form, but it included the same details and resulted from formulations of the same stresses. Most of it was planned before the hospitalization, but as will be seen in this chapter, important parts were developed, and modifications made, during the experience, in order to meet unanticipated problems. The plan is presented in the following manner because it makes most sense in retrospect this way, and because it parallels the discussions of stresses in hospitalization in the literature review and the previous chapter.

Following the treatment plan, the story of this hospitalization will be told as it happened, in chronological order. In this way, it will be seen that all the stresses and treatment orders, presented here in separate categories, actually interacted as part of a continuous experience.

Hospitalization Treatment Plan for Gail Burns

I. Prehospitalization Anxiety

A. Relevant Family Information:*

1. Burns have good reason for financial worries, as Mr. Burns is unemployed and has no family health insurance. They have hardly considered how they will possibly meet the costs.
2. Gail spent her first three months of life in the hospital, due to a doctor's mistake. At one point she was taken home and she nearly died, seemingly due to parental neglect. Thus, Burns have reason to be suspicious of doctors and guilty and mistrustful of their own care of Gail. Mrs. Burns is worried that the nurses will be better able than she to comfort and care for Gail. She even wonders whether she will be in the way.
3. Mrs. Burns dreads the hospitalization as it approaches: she is constantly nervous, nauseated, afraid of leaving the house, and skipping almost all meals.
4. Mrs. Burns has almost no friends to talk with; her husband is very distant now in the midst of marital difficulties.
5. It may be helpful that Mrs. Burns readily speaks of her feelings.

B. Interventions by surgeon during final pre-hospitalization clinic visit.

1. Inform parents that Gail will be in surgery 1½ to 3 hours, after which the surgeon will call them; and that then she will be in the Recovery Room for 2 to 3 hours.
2. Inform parents that on her return to the ward, she would:
   a. be bleeding and oozing from the nose and mouth.
   b. be in a mist tent.
   c. have an IV in her arm for 24 to 48 hours.
   d. have elbow restraints, to remain on for 6 weeks.

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*This is an abstracted summary of relevant family information from the more complete profile presented in Chapter II. Not part of the Treatment Plan per se, it is a necessary perspective to include in order to individualize the care.

    e. be on antibiotics and sedatives after surgery.
    f. be miserable and cranky for a couple of days.
    g. have to be discouraged from crying.
    h. remain in the hospital for about six or seven days after surgery, barring complications.
  3. Encourage Mrs. Burns to participate in Gail's care as much as she can without becoming too upset. Point out that the nurses are there not to replace her, but to assist her.

C. Interventions by me, during my home visits for observations.

  1. Discuss ward routine with parents and answer questions they might have.
  2. Repeat to Mrs. Burns that while rooming in, her participation in Gail's care is crucial, because she knows her daughter best.
  3. Establish a relationship in which the parents feel comfortable sharing anxieties and concerns about the hospitalization.
  4. Invite parents and Gail to pre-admission visit to the ward several days prior to admission, in order to become more familiar with the people and place.
  5. Offer parents help in trying to make financial arrangements for hospitalization. Sources could include Crippled Children's Service, State Disability, and referral to a Social Worker.

D. Procedure during preadmission visit.

  1. General tour and orientation to ward and to room in which Gail will stay.
  2. Interview of mother and father by the primary nurse assigned to Gail's care.
    a. learn about Gail's usual routines, habits, likes and dislikes.
    b. encourage mother to take a major part in Gail's care during hospitalization; assure her that she knows the most about how to care for Gail but that she can depend on the nurse for assistance or for relief when she wants a break.
    c. begin to develop a relationship in which the Burns feel free to share concerns and ask questions.

3. Provide time for Gail to explore the ward, play with the toys, become familiar with the people, all at her own pace.
4. Primary nurse, mother, and Gail play with arm restraints and mist tent. Try to make a game of it. Show mother how to apply arm restraints to a large doll, and how to remove them. Send the armboards home with the family so that Gail can play with them.
5. Suggest that parents bring Gail's clothes and favorite toys.
6. Allow time at the end for coffee and conversation.

II. Admission, Strange Place, Unfamiliar Adults, Change in Schedule

A. Relevant Family Information:

1. Strange place: Gail loves to play with toys, will be likely to enjoy playroom right away. She readily roams quite a distance from her mother, even in new places, loving to explore every square foot of territory, and can be reassured from a distance by a call from her mother.
2. Unfamiliar adults: Gail is typically outgoing, overcomes fear of strangers quickly. As a child that most adults consider engaging and beautiful, she is usually well responded to.
3. Change in schedule: Gail's feeding schedule is very similar to that in the hospital; her nap schedule is erratic and seems to have no specifiable pattern; she is accustomed to sleeping in the parents' bedroom and is quickly responded to in the middle of the night if she wants something.
4. Gail does not have speech and gestures that are clear to most people; only her mother can read them.

B. Preparation, as presented just above, should be the first step.

C. Admission routines will have been minimized by the interview in the preadmission visit. Other routines can be handled after family has settled in comfortably.

D. Painful and frightening procedures, such as blood drawing, should not take place until the child is acclimatized to the setting.

E. On the day of admission:

1. Allow Gail to play freely on the ward, her mother nearby.
2. Primary nurse should spend some time in pleasurable play with Gail and in relaxed conversation with the parents.
3. Parents should be given a list of people involved in Gail's care, their names and roles.
4. Parents should be given a list, perhaps in the evening, of the various aspects of Gail's postoperative care and their timing.

F. Make efforts to maintain Gail's usual schedule of eating, when food restrictions do not prevent it.

G. Gail should not be left alone awake, should not be left alone with a stranger (to her), and any new person should be slowly introduced in the presence of Mrs. Burns or the primary nurse.

H. The number of people involved in Gail's care should be minimized.

I. Before admission, Gail should be drinking from a cup, weaned from a bottle and pacifier, and be not too dependent on milk and milk products.

III. <u>Separation of Gail from her Mother</u>

A. Relevant family information.

1. Mrs. Burns will be rooming in, thus a physical separation will not be a problem.
2. Due to Mrs. Burns' extreme level of anxiety, we must be aware that she may be unavailable emotionally to her daughter, essentially a separation and to be responded to as such.

B. Primary nurse will help care for Gail from the start and should be the substitute caregiver in any separation if it is possible. Therefore, she must learn from Mrs. Burns how to best understand, approach, and respond to Gail.

C. If a separation does take place, make sure that any possessions that Gail would use as transitional objects are available to her.

IV. Frightening and Painful Procedures

A. Relevant Family Information.

1. In the past, Gail's responses to medical procedures have been mild.
2. When Gail is most upset, only Mrs. Burns can soothe her.

B. Never completely surprise Gail with a painful procedure with hopes of not making her nervous ahead of time.

C. Never perform a frightening procedure in the absence of the mother or other very familiar figure.

D. Always provide comforting afterwards.

E. Painful procedures should be done in a special procedure room, not in the bedroom.

F. Gradually transfer the performance of procedures that will be done at home, to the mother during hospitalization.

G. As Grover Powers said, "challenge all routine procedures and examinations and the way they are carried out, to insure that they are performed, not for their own sake, but really to help the patient and to advance the knowledge of disease." (Powers, 1948, p. 377)

V. Surgery and the Immediate Postoperative Period

A. Relevant family information.

1. This is likely to be an extremely anxious time for Mrs. Burns, as her tension level has built to this operation for months or a year.

B. Parents should be with child when she goes to sleep if possible.

C. If still awake when taken to operating room, a familiar nurse should accompany her.

D. In the Recovery Room, after surgery, a familiar person should be present to comfort her.

E. Provide Mrs. Burns companionship and emotional support during surgery if she seems to want it.

F. On Gail's return to the ward, encourage Mrs. Burns to begin comforting her and assuming some of the care. We may want to split the caring roles at first, Mrs. Burns providing the comfort and the nurse doing the more intrusive and uncomfortable parts. (As we saw in Brenda Kelly's hospitalization, this was an extremely important time in establishing the nature of the mother-child-nurse relationship.)

VI. Parental Anxiety

A. Relevant family information.

1. That information given relevant to Prehospitalization Anxieties is also relevant here.
2. In addition, in the hospital Mrs. Burns' care of Gail, in which she feels she cannot keep limits very firmly, will be on public display and may leave her even more insecure and unable to set limits firmly.
3. Following a successful operation, Mrs. Burns is likely to shift the focus of her anxiety to other things in her life, such as her marital difficulties.
4. In her favor is that Mrs. Burns is very accustomed to caring for Gail's ureterostomies and thus may find it quite easy to perform any necessary bodily procedures. She claims to be most competent in physical care and least in emotional care.

B. All interventions toward establishing Mrs. Burns' role as the leading and respected caregiver, developing an alliance with the nursing staff, and gradually increasing if indicated her assumption of Gail's care procedures, are important here. They have been mentioned above more than once.

C. I will provide Mrs. Burns a chance to express her anxieties in a counseling relationship to take place concurrent with hospitalization if it seems indicated.

VII. Sedation

A. The stress of sedation could be more usefully examined as: the problem of preventing a child in pain and under stress from crying.

B. Relevant family information.

1. Gail has difficulty getting to sleep under most circumstances; she struggles to stay awake.
2. Gail sleeps best on her back: this presents a problem because the surgeon wants her on her side or belly the first day after surgery.

C. Inform mother that Gail is not to cry any more than necessary.

D. Try to prevent crying without using sedatives more than necessary due to their effects of immobilizing or blunting the child's own coping mechanisms.

1. Mother should comfort, or primary nurse when mother is unavailable, trying to soothe and minimize crying.
2. Provide quiet diversions: familiar toys, record player, music box, mobiles, water play, favorite picture book, etc.
3. Provide analgesia (pain-relievers) if pain seems to be one factor causing the crying.

E. Sedate as a last resort.

F. Recognize that crying is an important avenue of emotional expression, and that a child prevented from crying will need opportunities of other kinds to express the feelings of pain or anxiety: e.g., movement and play, interpersonal interaction with perhaps very close and constant attention.

VIII. Restriction of Motion

A. This stress could be more usefully approached as: how to prevent Gail from putting fingers, toys, or anything else in her mouth, and from pulling out her intravenous line.

B. Relevant family information.

1. Gail loves to play with toys, takes great pleasure in achievements.
2. She generally moves quickly from one play item to another, rather than attending for very long at any one toy.
3. She is a markedly active child, loving to roam and explore.
4. She takes out anger on toys and in oppositional behavior.
5. She is her most expressive in close collaborative play with familiar adults--this is important in finding other avenues for discharge when she is restricted from moving very much.

C. Under close adult supervision, allow one arm free from the armboards at a time for exercise.

D. A special effort should be made to secure the IV particularly well and then to make sure the accompanying adult watch for and stop attempts to pull it out.

E. In order that these restrictions minimally restrict Gail from expressing herself in play and activity,

1. Provide toys that cannot injure the palate (e.g., Nerf toys).
2. Provide toys under close supervision that she can use to express anger or pain (e.g., hammering and noisy toys at times).
3. As early as possible, begin allowing for more movement, ambulation, moving out into the playroom, playing with more toys.
4. Encourage the use of the resources she has that are not restricted (e.g., legs, vocalization, eyes, ears).

IX. <u>Preparation for Home</u>

A. Transfer all nursing care procedures that will be done at home, to Mrs. Burns gradually over the course of hospitalization.

B. Try to ensure that the hospital ward stimulus is not preferable to that at home, making the return home a depriving experience.

C. Make certain that child is returning to schedules and routines, as determined by Mrs. Burns, that approximate home life.

D. Gradually leave Mrs. Burns and Gail more and more on their own in the hospital if they seem to be managing well enough.

E. Send home a list of instructions regarding medications, armboards, and anything else relevant to Gail's care.

IMPLEMENTATION

Preparation

The surgeon had spoken with Mrs. Burns during the final clinic visit about the surgery and planned hospitalization. He passed on the information outlined in the treatment plan above (I,B), and he suggested that she room in if that seemed best to her. The alternative was to visit infrequently, because Dr. Mombello felt that too much visiting led to too much crying. With this meeting, the formal aspects of preparation had begun.

During my visits to the home the final week before admission, I began a supportive relationship with the Burns in three discussions. Mrs. Burns, especially, took the opportunity to raise questions and concerns. She had always been a nervous person, but lately it had escalated to the point where she felt sick and nauseated, was eating almost no meals at all, vomited up the food she did eat, and had panicky attacks of unexplainable dread whenever she left the house to go on errands. She was desperately frightened of the coming hospitalizaion: "I don't know why. Maybe it is related to being in the hospital after Gail was born." She described in detail Gail's first three months of life in the hospital.

She had never felt sadness or discouragement during that time, had never once cried about it. As she told about it though, she was close to tears, and said, "Maybe all the feelings just build up over a long time inside and once in a while this has to happen (getting sick and nervous)." She recalled being helpless in those early months of Gail's life and she was afraid that in the hospital this time she would just get in the way. She feared that the nurses could comfort and care for Gail better than she could. Even with all her fears and anxieties, however, she had decided to room in because she knew that her daughter would be so afraid without her.

When I met with the nurses six days prior to admission, I had plenty to tell them about the Burns that would help in our preparatory planning. We all realized that this hospitalization may present more emotional problems than most, due to Mrs. Burns' fragile state of mind. We wondered during that meeting whether rooming in was the best idea. Maybe she would panic, paralyzed with dread, and as a result even require hospitalization for herself. Or, at the very least, she might upset Gail more than if she stayed home. But for two primary reasons it still seemed best that she room in. First, it appeared that replacing Mrs. Burns in Gail's care would be very difficult. She was obviously a competent care giver, in addition to which Gail was an almost non-verbal child whose gestures and sounds were interpretable only by

her mother. Secondly, we began to think that the hospitalization could be therapeutic for Mrs. Burns as well as for Gail. In one kind of setting, she might panic, might buckle under the stress, or perhaps stay away the way Mrs. Kelly did. But on the other hand, with the right kind of support, maybe she could master this crisis and care competently for her daughter. She might leave the hospital as a stronger woman, a more self-confident mother.

On the following day, the nurses and I met again to plan the preadmission visit. We knew it would be a crucial time in helping Mrs. Burns to feel at home. From what we knew of Gail, we expected that she would make herself at home in the playroom. The plan we developed is I,D above.

Mrs. Burns, her mother, and Gail arrived in the early afternoon on Thursday, four days prior to admission. Gail immediately took to the ward, and was allowed to freely wander around. She picked out toys to play with and went quite charmingly to strange adults to greet them. Mrs. Burns was quite obviously nervous: shaking somewhat, a little paler than usual, and biting her fingernails. Gail's appointed primary nurse talked with Mrs. Burns and recorded information regarding Gail's developmental history, feeding habits, sleeping patterns, favorite types of toys, temperament, and so on. Mrs. Burns' mother, much more composed, sat outside Gail's bedroom where the nursing interview took place; she kept track of Gail. The nurses showed

the family around the ward, encouraged them to have a cup of coffee. Mrs. Burns was pleased to learn that her meals would be provided along with Gail's ("although I haven't been eating anything") and that she could make one long distance call free of charge each day. She was told what Gail's schedule would be, just as the surgeon had already explained to her, and was told that the nurses considered her to be the primary caregiver while she was there. She was assured that if she wanted relief or "time off," a nurse would substitute for her, and that she would have all the help she needed. The goal was to let her know that she would not be supplanted, but rather would be supplemented and supported by the nursing staff in her role as Gail's primary caregiver.

We had arranged to have a mist tent (croupette) in the room, the way it would be after surgery. Gail had not gone to it spontaneously, so we brought her to the bed and encouraged her to explore it, feel it, maybe get inside it. We had put a very large Curious George doll in it, and a nurse taught Mrs. Burns how to apply and remove from him the armboard restraints that Gail would be wearing for six weeks. Gail refused to have anything to do with the mist tent, and it was only later that she would play with the arm restraints. She seemed to sense that this mock scene with George had something threatening in it for her. We sent the arm restraints home with Mrs. Burns for Gail to play with,

and planned to have the mist tent in the playroom on the day of admission. We wanted to reduce the threat-value of these things that would constitute part of the stress for Gail and her mother on the day of surgery.

Gail's nurse spent some time playing with her, and after a cup of coffee and some conversation, Mrs. Burns, her mother and Gail went home. Mrs. Burns seemed no less nervous than when she came, and Gail no less enthusiastic. Mrs. Burns' mother spoke with me before they left. She had some doubts about whether her daughter would "make it" through the hospitalization. "She held up so strong all through the hospitalization a year ago, kept it all inside. I'm just afraid it's all going to be too much for her this time. On the way here, in the car, she cried and kept saying that it wasn't fair to Gail to have to be cut again. When we got here, though, and actually walked in the hospital, she seemed a lot better." That feedback was echoed by Mrs. Burns when I made my last prehospitalization home visit the next day. She told me that she had been extremely nervous. "I didn't think I would make it." When she got to the hospital, she suddenly realized that the worst fantasies she was having were much worse than what the real situation was. And she felt better when she left. As we talked for another half hour, she brought up the other times in her life when she was so nervous, talked about her panicky feelings each time she left the house, and spoke of the presence of serious tension

in her marriage. It seemed that the preadmission visit had helped Mrs. Burns to experience some of her anxiety in a manageable dose, and that the counseling relationship we were developing was allowing her more and more expression of her fears.

I met one more time with the nurses, and we firmed up our plans for the day of admission. The overall strategy was that it be a time when Gail and her mother should settle in, feel comfortable, learn more about the operative schedule, and become more familiar with the hospital staff. It would be a time, before the addition problems of surgery and post-operative care, to minimize the stress of being in a new environment. (For plans, see II, C-E)

Day of Admission

Stresses: Admission, Strange Place, Unknown Adults, Change in Schedule, Frightening Procedures

Finally Monday came, and at 11:15 a.m. Mrs. Burns arrived along with her sister Nancy and Gail.

> Immediately, Gail is active, exploring, outgoing, teasing, playing. She goes right to the toy box which she discovered at the preadmission visit. She receives a real welcome from all onlookers: nurses, patients, and families, all of whom think she is an appealing, attractive, delightful little girl. Mrs. Burns seems a bit nervous, but much less so than on the preadmission visit day. That is, her hands are not shaky, and she does not seem to be walking on eggshells. She knows which room to go to, where she puts her coat. She has her suitcase with her and puts it in the room. Gail keeps her eye on her mother as she plays and wanders, and occasionally calls for her. I have the feeling that

> Mrs. Burns is pleased to see some of the same faces as she did before, and to hear various people greet her by name.

I had the feeling at that point that this might be one of the most social experiences Mrs. Burns had had for a long time, as their life at home was so quiet and she had so few friends.

From the very beginning, a precedent was established that during procedures that might be stressful for Gail, she was approached gently, unhurriedly, with a familiar adult (usually her mother) present to soothe her during and after the procedure.

> The nurse comes into the room and wants to take Gail's vital signs. Gail lets her pick her up, cautiously watching every step, seeming not sure yet how to respond. She allows the nurse to listen to her chest with a stethoscope and to take her pulse. Her mother is standing there, too, and Gail calls "ma" a couple times with a frown; she remains cautiously tolerant. The nurse lays her on her back in bed and takes her temperature rectally. Gail fusses briefly, checks with her mother, then just waits. She is cooperative but still cautious as the nurse takes her blood pressure, and then lets her pick her up to weigh her. The whole process seems remarkably smooth. After being weighed, she is handed to her mother; Gail seems relieved. She looks at the nurse for a moment from her mother's arm, then goes for a walk into the playroom again.

Under such optimal circumstances, these procedures were tolerable for Gail. At other times, with her tolerance level lowered by other stresses, the same procedures were cause for near panic.

During the afternoon, the mist tent was left in the playroom, in hopes that Gail would find her way to it. She

eventually did; she got inside it, tugged on it, and seemed to enjoy exploring it. By mid afternoon, both Gail and Mrs. Burns were becoming more relaxed. I recorded observations from 1:00 to 3:00 and summarized them as follows:

> During this two hour period, Gail is back to her explorations, her encounters with people around the ward, and her wanderings in and out of other patients' rooms. She keeps good track of where her mother is most of the time. Everyone is quite willing to play with and respond to her, and she has quickly developed relationships with almost everyone on the ward. Mrs. Burns and her sister talk during this time, sit and watch TV, and wander around the ward. It is a process of becoming more at home. Mrs. Burns has some brief chats with other mothers on the floor. She learns a little about why each one is there. She is curious about the other children. Gail is always coming back to her, requesting or demanding to be picked up, demanding water, wanting a toy, and so on. Mrs. Burns is really quite patient with all this and affectionate toward Gail.

In late afternoon, the Plastic Surgery Resident arrived on the floor to do Gail's physical exam. It is interesting that although the procedure here was no more intrinsically stressful than the one mentioned earlier, and although it was done under equally optimal circumstances (in Mrs. Burns' arms), Gail's reaction was strikingly different. The fact that this person was (1) a stranger and (2) a man in a white coat may have been the threatening factors that made the procedure intolerable.

> She protests violently throughout. He sees into her mouth and throat as she cries, which she never stops doing. He finishes the exam and then talks to Mrs. Burns to assure that she knows about the

> procedure and the postoperative restrictions. Gail continues to yell, looking at him and then away. Mrs. Burns puts her down to walk if she chooses, but she just stands there, holding her mother, screaming and wanting to be picked up again. The doctor leaves, and Mrs. Burns changes Gail's diapers. She remains cranky and irritable, in a way that seems to baffle her mother. After being changed, she walks out of the room, then back, then out and back again. Her mother gives her a cup of water. She drinks a sip and throws the remainder on the floor. Mrs. Burns quickly angers but just as quickly regains her patience and cleans it up.

The underlined portion above was a revealing observation. In the Burns' home, had that incident happened (as it had twice while I observed), Mrs. Burns would have grown quickly angry, scolded Gail, and demanded that she clean up the water. But instead, she inhibited her usual response, presumably because she was in the hospital and felt the public eye on her child care practices. We thought that changes such as that one could provide one more source of stress for Gail, because it meant that the responses she expected from her mother in helping her to control her impulses were changed, were more hesitant. Limit-setting was a problem that we had anticipated in Mrs. Burns. We were reminded that we needed to reinforce her sense of herself as a competent caregiver.

In the early evening, Gail's nurse needed to stick her finger and collect some blood. We didn't want Gail to associate her bedroom with painful procedures, so the nurse took her to a special treatment room, performed the procedure,

and quickly brought her back to her mother for comfort (Mrs. Burns did not want to witness the event).

> Gail comes back to the room, crying and upset. Her mother holds her affectionately, comforting her. They also hold Gail's toy kitten from home, and she calms down in her mother's arms. Gail strokes the stuffed kitten and is affectionate with her mother.

In the excitement of the new place, Gail had not taken a nap. She grew more and more tired and irritable in the evening. Finally she settled down to some quiet play with her mother, who by this time seemed quite relaxed on the ward. Dr. Mombello arrived at about 8:15 p.m. and spoke with Mrs. Burns. He reminded her about the operative and post-operative plans, and went over again with her the way Gail would look and feel after surgery. After he left, Mrs. Burns and Gail's nurse took her to bed, calmed her down, shut off the lights, and within a couple minutes, she fell asleep.

Mrs. Burns and I went to the conference room for a cup of coffee. She appeared to feel at home and relaxed. She proudly announced that she had eaten supper, a rare event for her in the past two months. She told me about relatives of hers who had been sick and had died of diseases, then about her fondest hopes for her husband and daughter, and soon she was talking angrily about Gail's birth when a doctor made the mistake of cutting Gail's omphalocele which led to one catastrophe after another in the hospital. It seemed

important to her to talk about these things--about deaths of relatives, iatrogenic catastrophes, and visions of her daughter's future. She was sharing hopes, resentments, and fears the night before the long awaited surgery. After about half an hour, I left the ward, telling Mrs. Burns that in the next few days I would be available if she wanted to talk at any time.

Day of Surgery

Stresses:
(1) anesthesia
(2) surgery
(3) recovery room
(4) mist tent
(5) arm boards.
(6) i.v.
(7) painful mouth
(8) no food
(9) sedation

It was the day of surgery, 7:00 a.m. Mrs. Burns and Gail were up.

> Gail was premedicated about half an hour ago, when she and her mother were awakened. Mrs. Burns is in her housecoat, on her cot, holding and soothing Gail. Gail is crying; as Mrs. Burns puts it, "fighting the medication." I speak with Mrs. Burns. She tells me that Gail slept well until 11:00 p.m. when she was awakened for her antibiotics. After that she would not go to sleep for quite a while, being upset at being back in her own bed. So her mother took her to bed with her in the cot and Gail slept well all night with her mother. Mrs. Burns said she was nervous late at night as well, but she too slept soundly with Gail in her arms.

A few minutes later, an attendant came to take Gail to the Operating Room. We were concerned that Gail have someone familiar accompany her, as she was still slightly awake. But the nurse assigned to Gail had not yet arrived for work. We asked the attendant to wait, but he said he had his orders and had to take her now. As a compromise,

another nurse, also familiar to Gail, went along with her and stayed with her in the hallway until she actually went in for surgery. By that time, she was very groggy, and surgery began shortly thereafter. The operation went well, excepting that Gail developed a bradycardia (slow heart beat) that was quickly remedied. Mrs. Burns stayed on the ward and took a lot of time showering, cleaning up her room, watching television, and visiting a little with nurses, other parents, and Mr. Burns. The nurses reported that Mrs. Burns was very nervous about the surgery.

Gail was taken to the recovery room. We discovered then that nurses from other units were not to care for patients there. Therefore, I joined Gail in the room (as a medical student, the same restriction did not apply to me. Still, they did not want me to care for Gail, as "those are the rules.").

> There the nurses start to prepare the mist tent on her bed. She is awake, very cranky, and fussy. There is a volunteer worker in the recovery room. I speak with her about Gail's need for attention and comfort. She attends to Gail, holds her in a chair, comforts her as the nurses prepare the bed. Gail calms down and lays her head on the volunteer's shoulder. There is not much bleeding at the mouth, and her breathing sounds good. Soon she is put in the tent, she gets very upset, crying and flailing about, needs a lot of the nurses' attention. She is given Tylenol for pain.
>
> In the meantime Dr. Mombello phones the parents on the CRCC. He tells them that Gail is finished with surgery, that it went well, that her palate is repaired, and that she is healthy and crying in

> the recovery room. She would be back in the ward in about two hours. He describes again how she will look when she comes to the ward.

It was then that the postoperative challenges began to present themselves. They were the same as in the previous chapter. A child frightened and in pain who was to be prevented from crying, from putting her fingers in her mouth, and from being too active at first. A mother, frightened, unconfident, and anxious, who had to see her child in pain, try to comfort her, and help to restrict and restrain her. The nurses and I met again to discuss postoperative care. After that meeting, I recorded

> Mrs. Burns should hold Gail to comfort her when she needs it, but Gail should be allowed to sleep as much as possible the first day. The nurses plan to encourage Mrs. Burns to do the comforting, making it clear to her that they can take over at anytime she needs a relief. The nurses will give the medications the first two or three days. The strategy will be to let the mother do all the comforting and let the nurses do the disliked procedures at first. Then Mrs. Burns will gradually begin giving the medications in preparation for going home, where it will be up to her. We are anticipating a problem with how Gail will lie in bed. She is supposed to stay on her belly or side, and according to her mother, she has always disliked being on her belly. We will have to play it by ear, just making sure that she does not lie on her back. We plan to give Mrs. Burns a schedule of what needs to be done to Gail and at what times. This would include medications, arm exercise, use of mist tent and IV, plans for feeding, etc. The point is to make it clear to Mrs. Burns what needs to be done, and give her a limited sphere of things to do at first, which she can do competently and confidently.
>
> It was a good meeting and I feel as if we are working together well.

It cannot be emphasized enough how important the working alliance between myself, the nurses, Dr. Ferholt, and Dr. Mombello was. With constant revising of plans and responding to circumstances as they arose, we needed close communication and cooperation. We could do it because we agreed on what was most important.

The time when Gail came back to the ward was critical in the developing alliance between the nurses and Mrs. Burns. As in the Kelly hospitalization, it was a time when the question arose as to who would be Gail's caregiver in time of greatest need.

> Gail comes back from surgery in her bed and in the mist tent. Her mother meets her at the elevator and follows the bed to the ward. Gail is crying, lying on her side, appears miserable. Her mouth is bloody. She is put in her room and the nurses quickly put her bed in order. Mrs. Burns stands off as the nurses work. <u>Gail's primary nurse coaxes her to hold Gail</u> and to sit in a chair by the bed. Mrs. Burns, at first hesitant, sits in the chair. Gail is given to her. She holds her, strokes her head, soothes her. Gail immediately calms down, is quiet, and in a few minutes is asleep. Gail, sleeping, is now put back to bed as they try gradually to work her into the tent without disturbing her. She wakes, cries. Her mother puts her own head down next to Gail's and looks at her. She quiets down again. The tent is finally put over her. She cries about it, but her mother reaches through the zippers in the tent and pats and strokes her and talks to her. She is soothed, quiets down, falls asleep.

The nurses recorded at that time that Mrs. Burns had a "very good, calming effect" on Gail.

Gail slept all of the early afternoon. But the whole event had taken its toll emotionally from her mother.

She stood tense, holding her stomach as I approached her and asked her how she felt. She said she had abdominal pains, was very nervous, and felt like vomiting. I asked her if she wanted to talk, to let the nurse care for Gail for a while. She agreed and we went to an empty room. As we entered the room and closed the door, she burst out crying. She turned away from me and apologized for crying, then went to the window and cried for several minutes longer. As we then talked, she remained weepy.

First she shared her fears that if she were to break down, she would be unable to care for Gail, who "doesn't know why this is being done to her." Then she talked about her vomiting. She said that it was part of her nervousness and that earlier in life she even wanted to die when she was nervous and vomiting. She said that she didn't want to die then because she had Gail to take care of. The subject of death seemed to stay in the air. She told of a vision of a dead child; it chilled me as I thought of Gail down the hall.

> 'It's maudlin.' I asked, 'What is?' 'Seeing dead people.' 'Have you seen any?' 'Yes, one. In seventh grade a kid with a large head died. He wasn't retarded or anything, he just had a big head. I don't know what was wrong with him.' 'Where did you see him dead?' 'At the funeral. His body was in the casket.' 'How did you feel?' 'It gave me the creeps.'

She shifted to talking about her husband. From the start she had wanted a closer relationship than he did. She used to fight to change him, but now had given up. Communication

between them was nearly non-existent. It was he who had most wanted a child, but now he didn't even care for her. Mrs. Burns had left him twice before, but each time returned within a week.

She seemed to be reviewing the problems in her life: her own inadequacies as a mother who might break down, her fears of Gail dying, and her painful relationship with her husband. They had accumulated inside her, and with an opportunity to speak of them, she cried and talked for an hour. It was hoped that this would also free her up to care for Gail. The thought was that in order to care for Gail as she expressed her pain, Mrs. Burns needed to be supported as she expressed her own worries.

And indeed, she was more prepared for her daughter after we talked. Gail was crying. Mrs. Burns held her outside the tent and she immediately calmed down. Mrs. Burns seemed more relaxed. The nurse commented that since the mother came back from talking, she was more confident around Gail. She held Gail for about half an hour, when the nurse helped put her back to bed. Gail cried, but her mother patted her and quieted her down. She fell asleep.

That evening Gail was crying and the nurse and Mrs. Burns were going to great lengths to try to get her to sleep. The following solution is an excellent example of the effectiveness of a mother-nurse alliance:

> . . . it was found that when her mother held her, although she became very quiet, she wanted to stay up and not go to bed. With Mrs. Burns' suggestion, the TV was turned up so that it would sound like home, Gail was given her favorite stuffed kitten to hold next to her face, and her mother left the room, in darkness. The nurse stayed and patted her as she fell quickly to sleep.

1st Postoperative Day

Stresses:
(1) I.V. remains until Gail is drinking enough liquids
(2) Arm restraints
(3) Painful mouth
(4) Sedation

Improvements:
(1) Mist tent is removed
(2) Clear liquids started.

This was a difficult day for Gail. Still very uncomfortable, she was growing increasingly energetic. She wanted to leave her room but the surgeon ordered that she stay in it. She had to be encouraged to drink juice so that her IV line could be removed. She was not supposed to cry but it seemed to be the best way for her to express how she felt. She was demanding of constant attention from her mother and nurse. The day seemed like a long struggle to keep Gail either content enough not to cry, or drugged enough to go to sleep.

At 2:00 a.m. Gail was awake and uncomfortable. Since pain seemed a likely explanation, Tylenol was given in a rectal suppository. She then slept most of the night. She woke three times, whimpering and whining, but each time was able to be comforted back to sleep by her mother and the nurse.

By 9:30 a.m., Gail and her mother were up. Gail was crying, and pointing into the playroom where she wanted to go. Mrs. Burns seemed tired, worn, and impatient to me. The nurse's comments, however, were that she seemed relatively patient under the stress. The nurse and Mrs. Burns were energetically trying to distract Gail from crying. The nurse was playing one record after another on a phonograph that was brought to Gail's room. She sang to her. She offered sips of apple juice. Finally Phenobarbitol, ordered to be given "when necessary," was given in a 20 mg. dose. For 40 minutes Gail grew perceptibly more tired, though still crying. With intensive constant attention from her mother, she finally fell to sleep. All the nurses had commented by that time that it was tremendously difficult to comfort Gail in her mother's absence. I wondered what would have happened if she hadn't roomed in.

Gail slept for two hours, but after she woke again, the struggle to prevent her crying continued; her mother and nurse sought to discover methods. For one thing, Gail was becoming more active and outgoing. She was encouraged to play with toys. But she just threw them on the floor or kicked at them. At first, her mother was discouraged by this, but it became apparent that she was enjoying rejecting and throwing and kicking toys. It kept her from crying. It was apparently an alternative outlet. So she was allowed to kick and throw books and toys at will. In the midst of this

encouraged aggression, however, she still sought security in her mother's comforting arms, and this also kept her from crying:

> Gail turns to mother a couple times, looks at her, says "ma" in a neither crying nor complaining way. Mother: 'What, punkin'?' Gail lays her head on her mother, and quiets down.

In the mid afternoon, Gail wanted desperately to leave her room. She continued to point to the playroom and cry. She was ready for more activity, a quick return to the larger world outside her room. Though the orders were to wait another day before going out, they seemed to be based on the surgeon's expectation that she would not be interested in activity until the fourth postoperative day. Mrs. Burns sought permission to carry Gail around in the unit. It was discussed and granted. As expected, Gail was delighted. This was an important example of the need to individualize care, to re-examine the real needs for each procedure in the context of the patient's needs and progress.

As the day passed, Mrs. Burns was finding Gail more and more difficult to care for. She seemed to be withdrawing into herself, and as she told the nurse at 3:00, she was "of no comfort" to Gail. I asked her if she wanted to talk, and as she agreed, we went to a pediatrics office off the ward. (Dr. Ferholt, who was supervising my counseling of Mrs. Burns, suggested that it might be important to her to leave the ward when we met).

I quickly found that her mind was still preoccupied with frightening imaginations. I will quote at length from that session, because it is a striking example of the kind of thinking that can accompany the anxiousness of a mother whose child undergoes surgery and hospitalization.

First she spoke of a dream she had had one time that a horse was injured, after which she said,

> Then the next day, we were driving a trailer with the horses, and we came to a sudden stop. One of the horses fell forward with her chest against a bar. She was really hurt. We went back and saw her and it had broken her ribs and broken through a large blood vessel. Blood was just gushing out all over the place. It made me sick. It was just pouring out. It was gory. I hate to even think about it.

In next telling me about a Psychic healer, who could unleash "bad forces" at will, she made it clear that in her opinion not only could people dream what would happen, but they could make things happen by thinking them.

> With the bad forces (she leaned forward, looked down at the street, and grew very tense), someone could kill a person walking down there on the street. It's creepy. I don't like to think about it. The powers of the mind; no one knows how much the mind can do.

My mind leapt to Gail, and I wondered if Mrs. Burns was telling me that she was afraid she might have inflicted harm on Gail, or was afraid that she might want to. After pointing out to me that doctors cannot understand and don't believe in these mental powers, she jumped to the question of why Gail had been born with defects.

> No one knows why. I've been told that already. But there must be a reason. There is a reason for everything. (What do you think it is? Do you think it had to do with something you did?) That's just what I wonder. Maybe God is punish-me. (Why?) For leaving Bobby just when I was pregnant. That's why I came back. I found out I was pregnant while I was gone from him. (How would things be between the two of you if Gail had not been born?) We would be separated, no doubt about it. I would never have come back. (long pause) (You are thinking about a lot of things these days.) All the time. It never stops. I wish I could make it go blank. I try but I can't. Only when I sleep. Thoughts are swimming around in there all the time. (What thoughts?) I think about my husband all the time. Of course, I worry about Gail, too. But I'm really not as worried about her. Deep down inside I know she'll be fine. But I don't know about my husband. My life with him is unhappy, and it shouldn't be. I wanted closeness in a marriage, and I don't have it.

She went on to complain at length about his reticence and distance. She mentioned that she might separate from him yet. But shortly thereafter, she was in touch with some fonder feelings:

> I want to make it work. I truly love my husband. I don't know why, but I do. I love him but don't like him.

It had been an intense hour, but as we walked back to the ward, she seemed less anxious. Then she sat down to a dinner of meat, potatoes, vegetables, and dessert, started eating without hesitation, and ate the whole meal. From a woman who had been anorectic for two months, it was a convincing display of the value of telling troubles to a supportive listener at a time of crisis. That evening, she impressed the nurses as more relaxed. She talked more with

other parents, initiating more conversations herself, and she was freer in leaving the ward for short walks. (It had been a concern of ours that Mrs. Burns would feel too compelled to take care of Gail every minute, so her increasing freedom was encouraging.)

Gail spent a surprisingly contented evening with her mother. Mrs. Burns had bought Gail a toy in the hospital gift shop after supper. It was a hammer and peg toy, and was part of the increasing armamentarium of ways to let Gail express herself without crying. Gail took right to it. She alternated between pounding with great vigor, and holding her stuffed kitten, for over an hour.

Mr. Burns came to visit that night. Gail was glad to see him. She reached for him and played with him. But Mr. and Mrs. Burns hardly spoke to one another. The tension was obvious. He left within one and one half hours and Mrs. Burns was tense and upset. By 10:30, Gail was sound asleep, and her mother lay down for the night in the cot next to her bed.

It was difficult for us to know what the hospitalization was going to mean for the Burns' marital relationship. On the one hand, it split them up for a week and could have been expected to create resentment in Mr. Burns. On the other hand, Mrs. Burns was getting a chance to look at the relationship from a different perspective, with some distance, and with some counseling support. It was a complicated issue for that family at that time, but in preparing for hospitalization

highest priority had of course been given to Gail's needs. This meant giving attention also to Mrs. Burns' needs as the primary caregiver, but in this family it did not seem indicated to give priority to the needs of the marital relationship. This, we expect, would be different with other families in other situations. It emphasizes again the need for individualization of care.

2nd Postoperative Day

Stresses: (1) IV still in, as Gail did not drink enough yesterday.
(2) Arm restraints.
(3) Still not supposed to cry.

Improvements:
(1) Officially allowed out of room today.
(2) The mouth seems less painful today.

Mrs. Burns and the nurses were concerned that morning that Gail had been crying a great deal during the night, that she demanded too much attention while awake, and that she slept for such brief time periods. In response, the Resident had ordered that her Phenobarbitol should be given in 20 mg. doses three times a day, just as Brenda Kelly had had (Chapter IV). But we were all aware of the stress of continual sedation, too. It was decided that sedation would be given only when it seemed that Gail needed a nap, hopefully approximating her schedule of naps at home (which was very flexible but usually included an afternoon nap). At other times, a full fledged anti-crying alternative program would be used (most of it was in use already).

(1) Give pain medication (Tylenol) more regularly.
(2) Provide close personal attention, consisting of play and comforting.
(3) Expand her toy curriculum to include more toys, books, and perhaps some water play.
(4) Encourage her somehow to drink more liquids, so that her IV could come out.

In a short meeting with the nurses to discuss the plans for the day, it was also decided that that was the day to start giving Gail her fluids on a schedule approximating her home eating schedule, and to begin transferring to Mrs. Burns the duty of administering medications to Gail.

That morning Gail and her mother both were showing signs of improvement in their temperaments. Mrs. Burns seemed very tired, but as the nurse's recorded observation read:

> Mrs. Burns more active in care with Gail,--doing things by herself--fluids, cleaning nose, finding ways to entertain. Expressing feelings more openly--'Oh, Gail, I wish you wouldn't throw things. I don't like that game.'

She was fairly easily irritated when Gail demanded a little too much, but with consistent support and relief from Gail's nurse, she was maintaining a constructive balance. Gail too was delicately balanced: with enough attention and responsiveness from her mother and nurse, she was active and zestful in playing with toys and books; she was vocalizing and gesturing to them; she once even studied a book for four minutes, longer than her mother ever recalled before; but if something went just a little bit wrong, or if attention lagged for a few moments, she grew frustrated and began to cry.

One of our objectives that day was to convince Gail to drink more juice. Unfortunately, she seemed to take oppositional delight in refusing to drink the oft offered juice. We decided on an indirect approach. Gail's nurse, her mother, and I all sat drinking juice as she played with toys. Within a minute, she was reaching for a juice glass, and she drank one and one half glasses in gulps.

After such a busy morning, during which Gail was able, with help, to constructively focus her aggression towards toys and books, she was calmer and slept much of the time from noon until 5:00 p.m. During the brief times she was awake, she seemed comfortable and more friendly toward her nurse. As one nurse recorded during that afternoon, Gail was "Happy!"

Mrs. Burns and I met again that afternoon in a counseling session. It had been scheduled by us without waiting for her request this time, in order that she could see that she did not need to be "sick" to get a chance to talk if she wanted to. Still, when we left the ward she complained of feeling nauseated, and told me she had vomited earlier in the day when she started up the stairs to the cafeteria. In that meeting, she focused on primarily three issues: (1) She wondered if she was "psychologically ill" and needed treatment. She had "wondered it a long time but never told anyone before." (2) She thought her problems of nervousness had started shortly after her marriage. She once

more was discussing the failings of her marriage, but this time seemed to consider more about what she could do to save it. (3) Finally, she said she was worried that she might be pregnant; her menstrual period had been due a week ago, and it was usually right on time. We agreed that it could have been late for emotional reasons and a pregnancy test would be appropriate in another week. It seemed that now that Gail's surgery was successfully finished, Mrs. Burns' anxieties were shifting more towards (1) her own psychological state, (2) the condition of her marriage, and (3) what would happen if she were pregnant again. I was hoping that by talking about them while still in the hospital, she could gain some perspective and consider seeking professional assistance.

During the two hours after we returned to the ward, the nurse recorded: "Mother seems much more relaxed; Gail feeling better." Mrs. Burns ate another full size dinner.

That evening, Gail took her first steps out of her room since surgery. She walked out to the playroom, pushing her IV pole with her as she went. She was pleased to be mobile again, and she managed to play actively even with the encumbrances of her IV pole and armboards. She was, according to Dr. Mombello's projected schedule, two days ahead of course in regaining interest in activity. He had already commented twice that she was pursuing an unusually rapid recuperative course.

3rd Postoperative Day

Stresses: (1) Arm restraints.

Improvements:
(1) IV removed in morning.

The nurses and I met first thing in the morning to discuss plans for the day. (1) We were concerned that Gail may be getting too much stimulation and attention from people other than her mother. Because she was so engaging when in good moods, it was tempting for most adults to play with her. Mrs. Burns, though, had mentioned that Gail would really be spoiled and not like going home. We decided to try and restrain ourselves, leaving Gail somewhat more to her mother, the way it was at home. (2) It was decided to encourage Mrs. Burns to begin giving Gail some of her medications, with the teaching and support of Gail's nurse. (3) The primary nurse would also work with Mrs. Burns on setting up a schedule for when to take Gail's armboards off for exercise. The schedule should be one that coincided with Gail's usual playtimes at home, and she should be started on that schedule while still in the hospital.

That was the most promising day yet. Mrs. Burns seemed stronger, more capable of holding to limits. The nurse's notes read:

> Complete a.m. care by mother. Seems relaxed. Very competent when caring for Gail. Appropriate responses.

Gail was out on the ward, exploring every foot of territory, making contact with other children and adults. She seemed

to be more independent, less demanding of attention from her mother. Mrs. Burns was able to comfortably watch TV. Occasionally she read books with her daughter. At one point, she left the hospital entirely, while Gail was napping, walked downtown to a department store and bought Gail and her husband some clothes. It was the first time in months she had gone out to a store without getting the least bit nauseated. She was quite proud of herself.

During the afternoon, Gail took her first bath in the hospital, in a sink near the nursing station. At the same time she was allowed to have one arm out of restraints at a time, as her mother and nurse were so closely supervising. She was delighted to splash the water, have her back rubbed, play with floating toys, and generally make a great mess. She surprised me with how verbal she became during the bath; she babbled to the adults around her at a rate far surpassing what I had observed in three weeks. Mrs. Burns seemed to like the bath time, too. We all were making the most of these pleasurable times, remembering well that up to this point Gail had been constantly on the verge of misery.

During the evening, both Gail and her mother remained relaxed and relatively energetic. They played with toys together and read books. Gail was taking great satisfaction in her play; she seemed proud of herself. She was put to bed at 8:00 and went right off to sleep.

It had been a remarkable day. Only three days before, Gail had had surgery; her mother had been nervous, phobic, and vomiting for two months. And still now Gail was wearing arm restraints, was not allowed to eat, her palate was filled with packing material, and she was still subject every day to intrusive procedures. Yet that day her temperament was high-spirited; she was actively invested in playing and in people; she was affectionate. And her mother, reciprocally, seemed more relaxed and healthy than in the three weeks I had known her. It seemed too good to be true.

4th Postoperative Day

Stresses: Arm restraints.

Gail was awake, crying and demanding, for several hours during the night. As a result, Mrs. Burns also slept very little. In the morning, they both were tired and irritable. Gail's clinging and dependency continued, and Mrs. Burns was demonstrating her irritability and anger at Gail more than ever. She had up to this point, even if she were upset with Gail, forced herself to be more patient, perhaps to keep up a favorable public image. This was the first time the nurses' observations included such things as:

> Mrs. Burns seemed like she was angry with Gail. Gail was irritable and asking to be picked up. Mrs. Burns refused, and walked away. This happened several times.
>
> Mother holding and rocking Gail. She seemed angry with Gail.

Similarly, I recorded:

> Mother walks and rocks Gail. Gail is fussy, demanding, dependent. Mrs. Burns is cold, distant, authoritarian. She looks very tired.

Gail took no nap and continued in the same way in the afternoon. Mrs. Burns grew more stern, angry, provided only the basic tasks of caregiving. She vomited in the morning, and talked with a nurse about her fear that she might be pregnant. At 3:00 p.m. the nurse's notes read:

> Mother becoming discouraged. Some impatience and anger at Gail's behavior becoming apparent. Freely expressing these feelings--'Gail, you're making me mad.' 'Stop that Gail.' 'Oh come on Gail, Mommy's tired.'

Both mother and daughter were receiving most supportive care from the primary nurse, but that wasn't enough. Mrs. Burns and I had a meeting scheduled, but she preferred not to meet.

It was a little startling to us to see such a marked change overnight. It was difficult to interpret just why it happened. Perhaps much of it could be explained by the sleepless night. If so, then we were seeing an example of what could happen in so many cases of children with sleep disorders even long after hospitalization. In Mrs. Burns, we may have been seeing a loss of some of the inhibition that kept her from being directly angry with Gail. Perhaps that in turn contributed to Gail's clinging temperament. They might both have been feeling the exhaustion of the whole experience, which for some reason was kept under control the day before. And Mrs. Burns may have been getting tired of being in the hospital now that the major work was done. The

first sign of this was her speculation that Gail wanted to go home:

> Gail is fussy, demanding, and completely focused on her mother. Mother tries to feed her. Gail opposes every move. Mrs. Burns is frustrated. Gail lies on floor kicking, screaming. Mrs. Burns says Gail is mad about something but she doesn't know what--- 'Maybe her mouth hurts. Maybe she wants to go home. I don't know.'

Gail and her mother both took a long nap before dinner. After dinner, Mrs. Burns was somewhat calmer and more affectionate toward Gail, who was in turn becoming more outgoing in playing with toys. So we were seeing again the importance of sleep, the need for both to have felt and expressed anger, and the need for Mrs. Burns to feel more relaxed and secure in order to provide Gail the security she needed to move outward from her mother. Mother and daughter went to bed at 10:00.

5th Postoperative Day

Improvement: strained fruits to be started today.

This was a Sunday. Fewer staff were on duty, and the general atmosphere was a quieter one. Gail and her mother were left somewhat more on their own. It seemed to make sense in preparation for going home, and because they were becoming more self sufficient. Mrs. Burns was giving Gail all of her Penicillin on schedule now, feeding her on schedule, and following a schedule of removing her arm restraints, one at a time, for exercise. Gail had again slept very poorly the night before, until her mother finally

took her into bed with her, after which she slept well. Even with the poor night's sleep, Mrs. Burns and Gail were holding themselves together much better:

> Mother tired today also but a little more rested than yesterday. Much more relaxed and patient with Gail today. Seems to have more energy. Initiating play with Gail. Taking full responsibility for Gail's care.

During the afternoon and evening, Mrs. Burns was taking a more and more active part in working with Gail on toys and books, noticing what Gail was trying to do and then helping her with it. She was trying to teach words to her as well.

> Mr. Burns, who visited last night, said that Gail's voice sounds different, sounds better, now that her palate is closed. She could puff her cheeks out in a way she never did before. Mother is trying to teach her to say things.

Mrs. Burns and Gail already seemed ready and willing to leave the ward:

> Gail takes people for walks, explores toys both on her own and with others. Occasionally she goes to the door and wants out. Mother always interprets Gail's pointing to places as wanting to go home.

During the evening, Gail was becoming more responsive to her mother's efforts at teaching her to say more words. She was imitating different kinds of sounds. This was new for her. Gail was put to bed and went to sleep at 8:30 p.m.

Day of Discharge

Gail and Mrs. Burns both slept well their final night in the hospital. Gail was up at 7:30 a.m., walking all over the ward, playing with toys, often going to the door and

trying to peer out. Mrs. Burns seemed relaxed and ready to go home. The nursing staff was trying to get their last enjoyable times in with Gail and were talking to Mrs. Burns. Several meaningful bonds had been made that now had to be severed--one of the difficulties of really caring for people appropriately.

I talked with Mrs. Burns for 20 minutes that morning. She was relaxed and energetic. About pregnancy: "if it happens, I will just deal with it--I like kids." About her husband--"Maybe I haven't really tried because of being so worried about Gail. That's why I've been so upset. It's obvious now. I wondered why I had so many problems and got so sick. Now it's gone!" Her appetite had returned and now was good. She couldn't wait to get home, clean up her house, and get going again. Her problems were seeming to be submerged again. I thought I could understand then why she had ceased her interest in more counseling during the hospitalization. After Gail was finished with surgery, a successful job done, the acute anxieties were less important than longer term problems for Mrs. Burns. But it may have been in her interest at that time not to stress herself by considering them all at once. She needed a rest. She started preparing to go home, and part of that was to stop meeting with me and talking about problems.

Mr. Burns came to the hospital. Mrs. Burns was making an attempt to communicate with him, to tell him about the hospitalization. He was more responsive than usual. After a developmental evaluation, and the surgeon's final examination of Gail, the Burns left the hospital about noontime.

Follow Up

When Gail arrived home, she went quickly around to all of her possessions and to the pet cats, and kissed each one. She was excited to be home, and checked every room. Then she did the most surprising thing of all. On her first birthday, she had been given a huge Raggedy Ann doll by her aunt and uncle. From the very start she had had an inexplicable fear of that doll and wouldn't go near it. Now, her first day home from the hospital, she went to it without hesitation, picked it up, and carried it across the room to set it in her own little chair. Whatever it had been about the doll that was frightening, she had overcome the fear during hospitalization.

Two days following discharge, I visited the home and spoke with Mrs. Burns. She explained that Gail was taking her medications without protest, eating large amounts of food with great satisfaction, and speaking several different sounds, such as "aaa" for "cat" and a word that sounded very much like "uck" for "duck." Mrs. Burns commented on another change in Gail, that she had "longer concentration than she has ever had." She would look at a book for several minutes

by herself now, which she had never done prior to hospitalization. Mrs. Burns was excited about Gail's maturing skills and talked at length about educational toys that had been at the hospital that she would like to buy for Gail. On the other hand, Gail was occasionally having temper tantrums that seemed more intense than ones she had before hospitalization and she was having trouble going to sleep. The first two nights home she had needed to go to bed with her mother in order to get to sleep.

Mrs. Burns herself was, as she had begun in the hospital, eating well, feeling much less nervous, and not at all phobic.

Observations of Gail during that visit confirmed what Mrs. Burns had told me. She was very interested in her toys, was looking longer than ever at books, and that day was showing no "temper tantrums" but rather was unusually loving toward her mother.

One week later I made another home visit. Mrs. Burns was still eating and feeling well. She had gotten her menstrual period three or four days after hospitalization. She had been out of the house on many errands and I asked her if they had bothered her the way they used to; she said they didn't, in fact, she had forgotten about that. Gail, too, was eating and feeling well, by both observation and mother's report. Mrs. Burns' observations of her daughter led her to think that "she seems older, more grown up. It's hard to

describe. She cries less and does more on her own." Gail, during the visit, was having a good time with her new ability to create a leak proof chamber in her mouth: she was experimenting with sounds, and sucking and blowing bubbles with delight. In addition to these signs of a maturing, healthy child, she had stopped having sleeping problems after the first two days, and was now falling asleep more easily and regularly than ever. Mrs. Burns seemed very proud of her daughter.

Four weeks after discharge, I telephoned Mrs. Burns. She said that things had equilibrated in the household by then. Gail was continuing her interest in speaking, and still seemed more grown up and mature than she had been before. She had no trouble sleeping and her temperament was good. Mrs. Burns, too, had retained the gains achieved during hospitalization: still eating, not vomiting, and not suffering from phobic anxieties.

Developmental Evaluations

Gail had two developmental evaluations, one just before admission and one just following discharge. The quantitative results were as follows: (see particular items on Yale Revised Developmental Schedule in Appendix, Part 2).

	Expected Skills at 15 months		Expected Skills at 18 months	
	Prehosp.	Posthosp.	Prehosp.	Posthosp.
Motor Skills	5 of 6	6 of 6	4 of 6	5 of 6
Adaptive Skills	5 of 9	7 of 9	2 of 6	3 of 6
Language Skills	2 of 4	2 of 4	3 of 6	3 of 6
Personal-Social	4 of 4	4 of 4	2 of 3	2 of 3

Quantitatively, we can see that Gail made progress from the prehospitalization scores to the discharge scores in areas of motor skills and adaptive skills, while not changing in language and personal-social areas. In particular, her gains were in (1) building of tower of two cubes in the second exam, (2) placing pegs in a pegboard more skillfully, (3) imitating the examiner's strokes with a pencil on paper, and (4) fitting a round form into a Form Board even with the Board being moved to a different position. Although the quantitative scores in Language Skills reflect no change, she actually progressed from using no vocalization in the first exam to frequent jabbering in the second.

In both examinations, she was friendly, playful, and teasingly oppositional at times. Her style of working was relatively fast and impulsive, with subdued intervals, though she was significantly better at concentrating on fine motor tasks after hospitalization. Mrs. Burns showed marked change, being considerably more relaxed in the second exam, and more interested in the achievements of Gail in the motor and adaptive areas.

Child Behavior Questionnaire

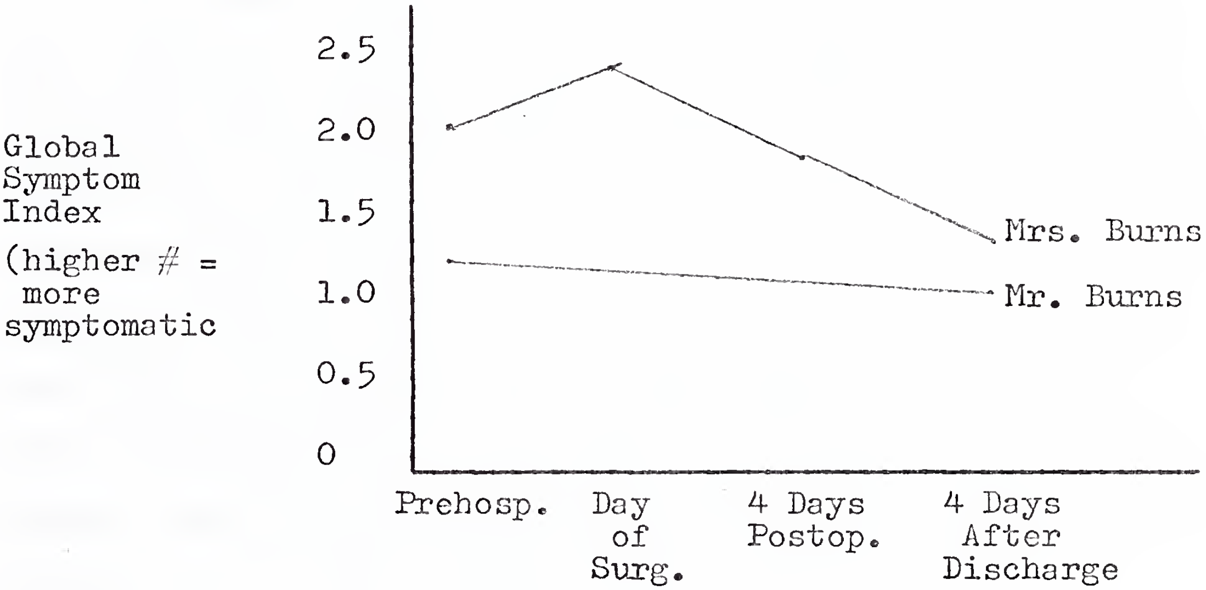
Mr. Burns took the questionnaire twice, once prior to Gail's admission and once four days following discharge. Mrs. Burns took it at those times as well as twice during hospitalization, once on the day of surgery and once four days post-surgery. Because of the lack of standardization of the questionnaire, an overall score would be meaningless. We analyzed the results item by item to see what changes took place over time in the parents' perceptions of their daughter.

Mrs. Burns' results demonstrate what we have described from direct observations and interviews: Gail was more upset by almost all measures in the hospital, mostly on the day of surgery and shortly thereafter. By the fourth day after discharge, she was as energetic as before hospitalization, she was as responsive and as comfortable, she was disturbed in her sleep patterns but less so than in the hospital, and she was speaking more than in the hospital. Mr. Burns' observations as recorded on the questionnaire were similar to those of Mrs. Burns except for thinking that his child was battling him more, was less responsive to him, and was crying more than before. This may indicate that Gail, who had seen him so little during the hospitalization, was not as responsive to him in particular, as she seemed to be at least as much or more so to her mother than before hospitalization.

SCL-90 Questionnaire

Global Symptom Index:

	Prehosp.	Day of Surg.	4 Days Postop.	4 Days after Discharge
Mr. Burns	1.2	--	--	1.1
Mrs. Burns	2.0	2.3	1.8	1.3



Factorial Symptom Indices: (Mr. Burns' factorial breakdown is omitted because only Mrs. Burns' scores showed meaningful change)

Factors	Prehosp.	Day of Surg.	4 Days Postop.	4 Days after Discharge
Somatization	2.4	3.0	2.0	1.25
Obsessive-compulsive	1.6	2.0	1.9	1.2
Interpersonal Sensitivity	1.6	1.3	1.4	1.0
Depression	2.3	2.8	1.9	1.5
Anxiety	2.7	3.3	2.5	1.5
Anger-Hostility	1.2	1.3	1.0	1.0
Phobic Anxiety	2.0	2.0	1.9	1.1

Factorial Symptom Indices (cont'd.)

Factors	Prehosp.	Day of Surg.	4 Days Postop.	4 Days after Discharge
Paranoid	1.2	1.2	1.2	1.1
Psychoticism	1.6	1.6	1.4	1.4

Individual Items

In every factor except one (Interpersonal Sensitivity), Mrs. Burns was either equally or more symptomatic on the day of surgery than she was prior to hospitalization. Again, in every factor except one (Interpersonal Sensitivity), she became less symptomatic four days after surgery, while still in the hospital. Finally, in every factor, she was equally (Anger-Hostility and Psychoticism) or less symptomatic four days after discharge than she had been at any time throughout the study. These changes parallel the story told by our descriptions as well as the changes in the Global Symptom Index shown in the graph above. As can be seen, the factors that registered the most significant changes in that direction were Somatization, Depression, and Phobia, confirming the clinical picture that showed Mrs. Burns becoming less depressed, less phobic, and freer of bodily symptoms such as vomiting during the course of hospitalization. The particular items that showed the most change in the positive direction were Heavy feelings in your arms and legs (1,4,1,1), Weakness in parts of your body (4,5,2,1), Hot or cold spells (4,5,4,2), A lump in your throat (5,5,5,2), Nausea or upset stomach

(5,5,4,2), Feeling low in energy or slowed down (3,4,1,2), Blaming yourself for things (4,2,1,1), Worrying too much about things (4,5,4,2), Feeling everything is an effort (2,4,2,1), Heart pounding or racing (5,5,4,1), Feeling tense or keyed up (5,5,4,2), Poor appetite (5,5,4,2), Trouble falling asleep (5,5,3,2), Awakening in the early morning (5,5,4,2), Sleep that is restless or disturbed (5,5,2,3). These items also confirmed the clinical picture in which Mrs. Burns was seen to make such dramatic changes in several areas of functioning.

Mr. Burns registered such low scores for symptomatology both before and after the hospitalization that there was not a very significant difference in any one factor from one time to the other. This went along with the clinical picture which revealed him as someone who is reticent, stoic, and unable to talk about any feelings. The only rating greater than "2" ("A little bit") on either questionnaire of his was a "3" ("moderately") for "feeling lonely" prior to hospitalization.

Summary of SCL-90

The overall results of the SCL-90 did nothing to alter our clinical picture. Mrs. Burns was very nervous and symptomatic prior to hospitalization, even more so the day of surgery, and dramatically improved during and after

the remainder of the hospitalization, to a level markedly less symptomatic than even the time prior to hospitalization.

Summary

We can conclude by combining all of our measures of evaluation, that:

1. Gail Burns was stressed by hospitalization, but at almost no time seemed to be overwhelmed and traumatized by stress. She made an unusually rapid recovery in levels of activity and temperament following surgery.

2. Although Gail was more temperamental and had more trouble sleeping for two days after discharge, she had returned to normal a few days later, and was showing distinct improvement in her ability to concentrate and her interest in vocalization. Her mother felt that she seemed more grown up and independent, yet still affectionate and enjoyable.

3. A sleep disorder acquired during hospitalization--waking up for several hours in the middle of the night--persisted for two days following discharge, but by one week following discharge she was sleeping better and more regularly than she ever had before.

4. Mrs. Burns, extremely symptomatic and dreading the hospitalization beforehand, required tremendous support in caring for her daughter, from the nurses and during counseling sessions. The impressions of the nurses, the child psychiatrist, and this observer were that Mrs. Burns became a

more self-confident, capable mother during hospitalization. She became more symptom-free and relaxed that she had been for months and was beginning to seek constructive solutions to ongoing problems.

5. Mr. Burns seemed to be little affected by the hospitalization by this observer's impressions and by the SCL-90 Questionnaire. He was quite uninvolved with supporting his wife or child throughout the hospitalization and the period afterwards.

CHAPTER VII

DISCUSSION AND CONCLUSION

This has been the report about the impact of hospitalization on young children. I began with a suspicion, based on my experiences as a medical student, that even after decades of research and modifications in hospital care, children were being unnecessarily traumatized by the stresses of hospitalization. The need for practical research into the means of helping children to cope in the hospital seemed paramount.

First I reviewed the literature to learn what others had discovered. Secondly I studied a 17 month old child admitted for cleft palate surgery to Fitkin 4, in order to learn first hand about the stresses and responses. Thirdly, I worked in collaboration with several nurses and a child psychiatrist to develop a treatment plan designed to make hospitalization a constructive and non-traumatic experience. Finally, we implemented the plan in the care of a 15 month old girl admitted for cleft palate surgery to the Children's Clinical Research Center. The plan was modified and extended as the case proceeded, based on ongoing evaluations, and the experiences of the patient and her parents were documented with the methods used in the first case.

I relied most heavily on direct observations with systematized diary-type recording both in the homes and in the hospital. This seemed to be the best possible way to preserve both the myriad details and the ever-shifting emotional flavor of the experience. My observations were supplemented by questionnaires, interviews, videotape, and developmental evaluations, as well as by observations made by nurses, the child psychiatrist, and the surgeon.

In the previous four chapters, the accounts of the two cases have been presented directly from the recorded data, the present chapter being reserved for brief summaries and more speculative considerations.

The first case, though studied primarily in preparation for the second hospitalization, drew out attention and concern due to the traumatic effects on the patient, Brenda Kelly. Her mother did not room in, and then only visited three times in eight days. Brenda grew more angry and rejecting toward her mother each time she visited. She was cared for by many different nurses during her stay, and could not have identified any one as her primary nurse. Her needs for comfort, food, and diaper changes were usually not met when the needs arose, but rather when the nursing staff found time to attend to her. She was repeatedly fed apple juice, to which she was "allergic," and as a result developed diarrhea. Because she spent long periods of time in soiled diapers, an extensive rash appeared after three days.

Some painful procedures were performed on her hastily, without emotional support, after which she was quickly left alone, in distress. Although sedated in hopes that she would sleep and not cry, she was still awake for many lonely hours, monotonously crying and reaching for each adult who entered the room. In this constantly drugged and overwhelmed state, she did not mobilize interest in play except for a few times when she was closely and caringly attended to. By the time of discharge, she was extremely angry and upset, unable to perform any items on a developmental evaluation, and indifferent to her mother as she was carried from the hospital.

Mrs. Kelly decided not to room in but felt guilty leaving Brenda alone. She felt intimidated and unwelcomed, and was upset that she could play no role in her daughter's care following surgery. She was angry that the nursing staff did not heed her warnings about the apple juice and that Brenda's diapers were changed so infrequently. At home, she grew more nervous and depressed, and developed somatic symptoms of tension. She thought she heard Brenda crying at night. When she visited, it was painful for her to be rejected by her daughter. Against her original intentions, she paid no visits after the third postoperative day.

It must be emphasized that the nurses involved in Brenda's care were competent and conscientious. They carried out the surgeon's preoperative and postoperative orders

carefully and efficiently. Several of them were familiar to me from my rotation as a medical student on Fitkin 4. I knew that they were dedicated to good nursing and that they cared very much about children.

It was therefore a surprise that not one of them recognized the emotionally traumatic aspects of Brenda Kelly's experience. It was their unanimous opinion that she had adjusted well and had not been upset except for the times her mother had come to visit.

I was thus led to the disturbing and perplexing conclusion that, in at least one case, <u>concerned and well-meaning individuals failed to notice the traumatic experience of a hospitalized child for whom they were caring</u>.

Whether this was an unusual or typical case in this respect we have no way of knowing from this project. I recall that during my five week rotation on Fitkin 4, not one routine surgical patient as distressed as Brenda Kelly came to my attention. I suspect that I, in that role, would have overlooked, as the nurses had in theirs, the disturbing aspects of this case. It raises the possibility that other children as well are overwhelmed in the hospital without attracting the notice of those responsible for their care.

While this research was not designed to explore why Brenda Kelly suffered as she did or why her suffering escaped recognition, my observations and experiences during the

project have led me to suspect at least two causes. One involves constraints imposed upon the Fitkin 4 medical-nursing system from outside its control and the other involves constraints it has imposed upon itself.

First, I was impressed that even those nurses most humanely motivated to foster the children's emotional adjustment, spent most of their time hurrying up and down the long hallway, in and out of rooms for procedures and basic physical care, consulting with interns, residents, and other nurses, and recording notes on the many patients under their jurisdiction. The provision of "TLC" to children and parents was not incorporated into the nursing care role requirements and remained a sporadic "extracurricular" activity. The design of physical facilities and the large number of children assigned to each nurse, both of which were determined from outside the medical-nursing system, must be held in part responsible.

These external constraints are insufficient, however, to account for the degree of deprivation and trauma suffered by Brenda Kelly. The existing facilities and available personnel were not optimally utilized and organized to evaluate and treat her emotional needs. As three examples, we can recall the parents' role on the ward, the individual nurse-patient relationships, and the place of behavioral observations in the nurses' and doctors' notes.

As described in Chapter III, parents are poorly accommodated on Fitkin 4, although their importance to the children, in theory, is fully recognized by the staff. A ward committed to including parents can make ingenious use of even the most inadequate facilities, as Hardgrove and Dawson (1972) have inspiringly described in Parents and Children in the Hospital.

Also described in Chapter III was the way in which the modified Team Assignment nursing system used on Fitkin 4 discourages individualized nurse:patient relationships. While a few of such relationships exist by preference of any given nurse for a certain child, the formal system maximizes the number of children cared for by each nurse and therefore minimizes the amount of contact with each one.

The low priority on the child's emotional care is reflected also in the nurses' and doctors' notes, which contain a paucity of behavioral observations in contrast to meticulous measurement and recording of vital signs, intake and output, and the condition of the particular medical problems. While behavioral observations are undoubtedly shared by word of mouth, a concerted and conscientious approach to the child's emotional adjustment by the many people involved in her case requires an ongoing recorded data base, just as is required in medical treatment planning.

If a true commitment is to be made to reducing emotional trauma in early childhood, it must be made by the individuals working daily for children's well-being in

hospitals. And it must by made by those who organize the medical-nursing care systems in which those individuals work, employing facilities and personnel in the most humane and resourceful manner. Finally, our hospitals, communities, and society as a whole will have to provide the resources necessary to support lasting and consistent improvements.

The needs for these commitments, and models for their implementation, have been pointed to for many years by people in nursing, pediatrics, social work, and psychiatry. (Petrillo and Sanger, 1972; Stacey, 1970; Hardgrove and Dawson, 1972; Robertson, 1970; Oremland and Oremland, 1973; Plank, 1971). Yet change has come slowly and inconsistently. These same authors have echoed many from earlier decades in citing the reasons that progress has come slowly: the inherent resistance to change in established systems; the belief that more humane care and the inclusion of parents will only require more work without more reward; the expectation that the expenses of the kind of care needed will overburden the already financially overburdened health care system; and the attitude that holds output for psychological care to be frivolous when even technical medical facilities are inadequate. The authors cite the need for changing people's attitudes and for demonstrating the economic feasibility of humane, family-centered care.

I would add one consideration to these from my personal experiences in this project. Fully recognizing and treating the pain and anxiety of a young child is tremendously difficult and draining under any circumstances, favorable or unfavorable. As I sat for so many hours and watched Brenda Kelly deteriorate emotionally, I wanted to leave, I wanted to deny its importance in her long term development, I wanted to blame nurses and parents for the unhappiness I saw, and I wanted to do something, anything, to help her. Nurses on surgical and medical floors have told me they would never work in pediatrics: "those sick and crying kids just tear me apart inside." The surgeon in this case, concerned about what he does to children, wanted to deny that children under the age of two feel any pain in their mouths after surgery on their palates.

No one wants to take responsibility for the pain of a child unless they can actually do something to help, in which case it becomes an extremely gratifying experience. Mrs. Kelly, caring most deeply of all about Brenda, could not remain and watch her daughter in pain and distress, even knowing that she was needed, unless she could help in the care: "I feel so helpless; I guess I should just go home." Nurses are in a particularly anxiety-provoking position. Not only are they exposed daily, hourly, to sick children in pain; they also must perform intrusive and frightening

procedures upon them. It is adaptive and not surprising, that in a hospital setting not staffed or designed to really meet the children's emotional needs, compassionate nurses will develop ways of not seeing or of not consciously admitting much of the children's unhappiness. This can be done at the individual's level and at the systemic level of nursing organization and role definition. (See the best example of this type of analysis in Menzies, 1961, The Functioning of Social Systems as a Defense against Anxiety, a study of a nursing service in a general hospital.) While adaptive for the nurses, it perpetuates the non-recognition and non-treatment of the children's distress, and contributes to the stubbornness long faced in trying to humanize hospital experiences.

This project was not designed primarily to prove or even demonstrate the potential ill effects of hospitalization shown convincingly in the literature for decades. But the traumatic impact seen in the first case was of great importance and deserved some discussion. The major aim, embodied in our second case to which we now turn, was to explore the ways in which to provide non-traumatic and constructive care to children and parents in the hospital.

With the application of our treatment plan and the use of creative solutions to problems that arose, Gail Burns and her mother seemed to cope well with the hospitalization and to emerge from it stronger and more confident

than before. The child, subjected to a multitude of deprivations, restrictions, and painful intrusions, was almost never overwhelmed by the stresses. She was helped by her rooming-in mother and the nursing staff to maintain her anxiety in a manageable state and to employ her own resources for adapting to the difficulties. She rapidly recovered her spirited temperament and her investment in physical activity, toys, books, and people. Throughout the experience she relied on her mother for comfort and security. By the time of discharge, quite back to normal in nearly every respect, she was demonstrating a longer attention span in her playing and a greater interest in vocalization. The difficulties that she had in sleeping disappeared after two days at home. One week after hospitalization, her mother felt that Gail was acting more mature and more independent.

When Mrs. Burns was first seen, she was plagued with nervousness, vomiting, anorexia, and phobic anxieties, all of which were increasing as hospitalization approached. While rooming in, she received daily counseling and a continually supportive alliance with the nursing staff in order to manage her tremendous anxiety and to remain emotionally available to support her also anxious and fearful daughter. By the time of discharge, she was more relaxed, was no longer vomiting, was eating large meals with pleasure, and had lost all traces of her phobic anxieties. It was the impression of

everyone involved that she was a more self-confident mother, better able to set firm limits on Gail's aggression, and that she took more pride in her daughter's accomplishments.

It has thus been convincingly demonstrated that we are capable at the present time of making a young child's routine hospitalization for surgery non-traumatic and constructive psychologically as well as beneficial medically. Without doubt, this is the most significant single finding of this project.

The means of doing this in the one case of Gail Burns have been described in Chapter V. The account serves to illustrate a few of the many specific ways in which children and parents can be helped to cope with stresses in the hospital. But due to the need to individualize care to each new patient, the particular setting, and changing circumstances during the case, our account is not useful as a prefabricated, transferable set of orders. It is useful in demonstrating several principles which underlie the provision of a constructive hospitalization, applicable to other wards and cases in different specific ways each time. I will discuss here a few of the most important principles that we employed.

1. Delineation of Goals

In general we wanted to minimize the probability that the hospitalization experience would be traumatic for this 15 month old child. More specific goals which guided our

approach included those which we believed would further the development of Gail's coping abilities: her uses of sensorimotor abilities, language skills, emotionally expressive functions and cognitive capacities to solve problems and cope with stress, increasing her sense of mastery for having successfully managed the threatening experience. We believed also that we might be able through work with the child and mother to improve the quality of the mother-child relationship. In the absence of such constructive goals as these, the care can easily be centered only around the definitive goals for surgical repair to the exclusion of emotional considerations.

2. Development of the Treatment Plan

The conceptualization of goals, without incorporating them in specific terms in the treatment plan is of little help to the hospital staff. The plan had to enumerate those factors that were likely to be stressful for the child and mother and specify various alternative ways to help them cope with the stresses. The treatment plan had to be carefully monitored and adapted since its success depended upon its being dynamically applied to suit the particular situations that arose with child and parent.

3. Consideration of Individual Developmental Characteristics as a Guide in Alleviating Stress.

It was necessary to remain aware that Gail's responses to stress depended not only on the objective character and

severity of it, but on many individual factors, including: her endowment, her stage of development, her previous experiences with similar stress, her current physiological and psychological state, the context of the stress, and the response of significant adults in her world. This implies the need for a detailed profile, obtained preferably before admission, plus ongoing evaluation and management planning based on changing circumstances. Utilizing these data we expected to keep the amount of stress at any particular time within limits manageable by Gail, with maximal use of her own resources and her mother's support.

4. Inclusion of Parents

As described in Chapter V, it was a difficult challenge to include and support Mrs. Burns. Our efforts were motivated by the recognition that the parent is the most important person in a 15 month old child's world. No one else can bring such security in times of need; no one else can interpret her messages so well or provide comfort so effectively. But parents may find it very difficult to provide the needed support if they are unsupported themselves through alliances with staff members and, at times, supportive counseling. This case provided an excellent example, in our opinion, that admission of child and parent together can significantly enhance the parent's self-confidence and the child-parent relationship.

5. Mutual Support among Staff Members

As we have discussed, becoming involved emotionally with a child and parent in the hospital can be quite draining for nurses. To remain effective and supportive, a nurse needs support just as a parent does. On the CCRC, this was provided in an impressive degree of intrastaff collaboration. The collaboration was essential also in the exchange of information and the coordination of planning. It is difficult to imagine effectively coordinated constructive emotional care without significant collaboration.

6. Observation and Evaluation

The staff must remain aware of the patient's and parent's adjustment throughout the hospitalization. This requires an emphasis on objective observations as well as subjective involvement. It is encouraged by a systematic and frequent recording of behavioral observations in the nurses' notes.

Conditions which favor putting these principles into practice include a general atmosphere of benevolence and support. The commitment to creating a psychological climate which facilitates recovery from the effects of an illness or surgical procedure will come across in innumerable ways not specified here. The ways in which facilities are utilized for the family's comfort and security, the courtesy and respect expressed by staff members for each other and for the

patient and parents, and the satisfaction expressed in the work will all contribute to an atmosphere that is warm and secure in contrast to the usually more sterile and impersonal hospital ward. This more general component of constructive care, I want to emphasize, does not require ideal conditions and plentiful resources. It is an attitude that includes a willingness to improvise the available resources for the family's comfort and well-being.

The implementation of the foregoing principles requires compassionate, intelligent, creative solutions. It depends on experienced people who know the many different ways to sponsor a child's play, to give physical care, and to do procedures in order to create an emotional climate which helps the child control tension and be as comfortable as possible. They also must be able to support and supplement the parents' involvement in the care in a way which does not place a strain on the parent-child relationship. These skills are not developed intuitively and they are not employed automatically. They need to be incorporated into training programs, including inservice education. And they need to be supported through the creation of settings by hospitals in which they can most effectively be employed.

Conclusion

In this thesis, we have recognized and documented a problem. We have conceived of solutions and put them into

practice. We have evaluated the results and discussed the implications. It was not a new problem. The solutions were suggested decades ago and have been tried and proven effective innumerable times. It is frustrating to some of us that the problem has lived on while treatment in other aspects of pediatrics has progressed so steadily. We hope that by having carefully documented and presented vivid examples of both problems and solutions, a small contribution has been made toward bettering the care of children and parents in the hospital.

APPENDIX: PART ONE

HISTORICAL PERSPECTIVE ON CHILDREN IN THE HOSPITAL

<u>Prehistory</u> - 1772 - mid 19th century

Children's hospitals are a fairly recent development in Western Civilization. Two hundred and four years ago, well before the first ones began, George Armstrong wrote the following objections to their establishment, objections that forecast problems to be faced by such institutions:

> Several Friends of the Charity have thought it necessary to have a House fitted up for the Reception of such Infants as are very ill, where they might be accommodated in the same Manner as Adults are in other Hospitals. But a very little Reflection will clearly convince any thinking Person that such a scheme as this can never be executed. If you take away a sick Child from its Parent or Nurse you break its heart immediately: and if there must be a Nurse to each Child what kind of a Hospital must there be to contain any Number of them? Besides, as in this case the Wards must be crowded with grown Persons as well as Children must not the Air of the Hospital by thereby much contaminated? Would not the Mothers or the Nurses be perpetually at variance with one another if there were such a Number of them together? Would not the Children almost constantly disturb each other with their Crying? Supposing only a few in one Ward should be taken ill of a Vomiting and Purging, to which Infants are so very subject, would not this presently infect the Air of the Ward and very probably communicate the Disorder to other Children confined there? Yet this is one of the principal Diseases where a Hospital might be of service to the Infants, were it not for insuperable Objections just now mentioned. Add to all this it very seldom happens that a Mother can conveniently leave the Rest of her Family to go into a Hospital to attend her sick Infant. (Still, G. G.: <u>The History of Pediatrics</u>, 1772; as quoted from Powers, 1948.)

Though a few reformers were proposing that hospitals be built for children, society was not yet ready. The role of the child in the early nineteenth century was, if he or she happened to live beyond early childhood, as an important economic resource, as inexpensive labor. Children were regarded almost like another species and in the upper classes often were sent out to the country to be nursed by other women until they grew past infancy.

The conception of the child was beginning to shift in the mid-nineteenth century, as we can gather from the Earl of Shaftesbury's famous denouncement of the exploitation of <u>Children in Mines and Collieries</u> (Kessen, p. 45). Kessen writes:

> Shaftesbury continues what the medical reformers of the previous century had begun; the child was becoming a true human being, valuable to society, requiring special care, and, though this point was made only feebly in early nineteenth century England, interesting in his own right. (p. 44)

Naturally, such changing sentiment provided more fertile ground for the birth and growth of children's hospitals. In addition, Darwin's studies on <u>The Descent of Man</u> fueled scientific interest in the child. (Kessen, p. 44)

<u>Birth of Children's Hospitals - Mid 19th Century</u>

In the midst of increasing humane and scientific regard for children, the earliest hospitals were appearing in the middle and late 19th century, and their original nature was influenced by at least three trends. First,

they were patterned after the already well-established adult hospitals: "They inherited the same oblong wards and cheerless corridors. They imitated their methods of staffing and of nursing. They pursued their methods of research." (Spence, 1947) The child's unique needs and qualities were not reflected in the architectural layout. Unfortunately, even today we are still hampered by this legacy. Secondly, the hospitals resembled the foundling homes for abandoned children. "Children's hospitals were regarded too much as refuge homes for slum children and too little as places for scientific study of the diseases which might best be treated there and of the methods by which they might best be nursed." (Spence, 1947) Thirdly, because of an enormously high infant mortality rate, the fear of cross infection on the wards dictated very important policies, such as isolation of each child, the prohibition of visiting, minimal handling, and the refusal to admit children under the age of two years.

Era of High Infant Mortality - 1860 - 1930

When, in the late 19th century, children under the age of two years were finally admitted to hospitals, they did die at an alarming rate just as they did in other infant institutions. The mortality rate for infants in hospitals and in foundling homes ranged from 70 to 100% (Chapin, 1915; Brenneman, 1932; Spitz, 1945). The extreme

measures taken to ensure isolation and sterility, on retrospect seen to be overcautious, reflected a single-minded view that death and illness were caused by germs and by poor sanitation. Important as the discoveries about infectious disease, malnutrition, and other childhood illnesses were, any interest in the psychological impact of institutionalization and its relationship to morbidity and mortality were eclipsed by this outlook for several decades. Even with the strict measures taken, the mortality rates only very gradually declined.

Era of Psychological Awareness - 1920-1940

In the first three decades of this century, as Freud and others were emphasizing the importance of early life experiences, and as the hospital infant mortality rates only gradually fell off (Bakwin, 1942, p. 39), voices of sensitive physicians and reformers were calling out for a closer look into the effect of the hospital environment on the young child. Perhaps sterility, isolation, separation from the mother, and general lack of stimulation were more deadly than cross-infection per se. Brenneman established a rule that every baby should be picked up, carried around, amused, and "mothered" several times a day (Brenneman, 1932). Parrot, a French clinician who had wide experience in foundling homes and hospitals, concluded that the failure of children to survive in these institutions was due to lack of

adequate stimulation (Parrot, 1922, as cited by Bakwin, 1942). Durfee and Wolf in 1933 claimed that hospitals "succeeded in sterilizing the surrounds of the child from germs but . . . at the same time sterilized the child's psyche. Even the most destitute of homes offers more mental stimulation than the usual hospital ward." (Durfee and Wolf, 1933, as cited by Spitz, 1945). Bakwin, in 1951, recalling those early decades, asserted that the "principal lethal factor previously was psychological neglect, not infection; and the efforts to protect babies against infection by isolating them intensified the emotional deprivation." (Bakwin, 1951)

By 1940, after applications of these new discoveries and with the introduction of the antimicrobials in the late 1930s, cross infection and high mortality rates were not such crucial issues. Bellevue Hospital in New York City was registering an infant mortality rate of less than 10%, comparable to others throughout the country. (Bakwin, 1942)

Era of Focus on Maternal Deprivation 1940-1950

Now that children survived, the other drawbacks of institutionalization became apparent. There was widespread recognition that hospitalization of infants was damaging both physically and psychologically, and there seemed to be near unanimous agreement that maternal deprivation played a major causal role. (Lowrey, 1940; Pearson, 1941; Jackson,

1942; Edelston, 1943; Freud and Burlingham, 1944; Bakwin, 1942; Levy, 1945; Spitz, 1945; Spence, 1946; Powers, 1948) But there were emerging already, different interpretations of the reason that maternal deprivation was so important. The psychoanalytic literature reflected a belief that the damage resulted from separation from the particular mothering figure, the primary object. Spitz claimed that "stimulation by the mother will always be more intense than even that of the best trained nursing personnel. . . The presence of the mothers could compensate even for numerous other shortcomings." (Spitz, 1945) Edelston wrote, of children in the hospital, "their symptoms become intelligible as manifest or latent exhibitions of the separation anxiety or reactions to overcome it." The pediatric literature, also recognizing that the mother was the most important person, reflects slightly greater emphasis on the child's dependency on the external world and on the need therefore for "mothering care" in general. (Bakwin, 1942; Power, 1948; Jackson, 1942) "The young infant is dependent on the environment for gratification of his psychologic needs just as he is for satisfaction of his nutritional needs." (Bakwin, 1942) Bakwin instituted appropriate prophylactic measures in his hospital:

> Mothering and cuddling are as much a part of the nursing care of the baby as are bathing and dressing. Interns are encouraged to pick up and play with the babies during their free moments. . .

> Infants who remain in the hospital for prolonged periods are assigned to particular interns for their special care. The parents of sick infants, instead of being excluded, are invited to the ward and are encouraged to hold and fondle their babies. (Bakwin, 1942)

Although I point out the slight difference of emphasis because of its later development into a controversy over the importance of separation (later in the chapter), most significant at that time was the almost exclusive focus upon the separation stress and the underplaying of other noxious aspects of hospitalization. Gradually since then we have come to a more balanced appreciation of the stressful factors for a child in the hospital.

Modern Era 1950-Present

As the 1940s ended, the modern era of studying psychological aspects of hospitalization began. This is reflected in the literature of the 1970s, which refers with such frequency to the speech by Grover Powers in 1948, "Humanizing Hospital Experiences," and to the classic studies by Prugh et al. (1953), Jessner, et al. (1952), Bowlby et al. (1952), Langford (1948) and others. This era is characterized not by very many new questions than those raised in the 1940s, but by increasing sophistication in asking them, trying to answer them, and modifying hospital practices to reflect the growing understanding.

REVIEW OF LITERATURE

In this section, I will review the literature that was important in the formulation and realization of this project, but not all the literature on hospitalization of young children. Comprehensive reviews can be found in Vernon et al. (1965) and Yarrow (1964). The reader wishing to find the literature since 1965 can find bibliographies in the following relevant publications: Robertson (1970); American Academy of Pediatrics (1971); Stacey et al. (1970); Hardgrove and Dawson (1972); Petrillo and Sanger (1972); Plank (1972); Oremland and Oremland (1973); and in The Bibliography on the Hospitalized Child (1973).

The organization of this review parallels the organization of my thinking as the project approached. I sought answers to the following questions:

1. What are the developmental tasks, the strengths, and the vulnerabilities of a child in the first half of the second year of life which have special relevance for the experience of illness and hospitalization?

2. What is the nature of the cleft palate defect and its treatment? What are its effects on psychological development and on the parent-child relationship?

3. Are children of this age distressed during a brief hospitalization?

4. Are children and families distressed shortly following brief hospitalizations for young children?

5. Have long term psychological consequences of hospitalization during infancy been recognized?

6. What characteristics of children and families increase their apparent vulnerability to the impact of hospitalization?

7. Can hospitalization be psychologically beneficial for a child and family?

8. Which factors in hospitalizations seem to be most stressful?

9. What has been and can be done to minimize traumatic possibilities and to maximize beneficial possibilities of hospitalization?

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1. What are the developmental tasks, the strengths, and the vulnerabilities of a child in the first half of the second year of life which have special relevance for the experience of illness and hospitalization?

For decades it has been recognized that the age and developmental stage of a child is an important determinant of the response to hospitalization. At first, a rather global view prodominated: the younger the child, the more vulnerable. After all, the youngest infant depends totally on the environment for nourishment, protection, and affection. As Levy (1945) put it, she* "had less experience in social contacts and visits outside the home and less comprehension of what is to take place." Soon clinicians began to notice that it was not quite correct to assume that the younger the child, the more vulnerable she would be to hospitalization. Especially important have been studies by Prugh et al. (1953), Schaffer and Callender (1959), and Vernon (1965, 1966). Prugh, corroborating earlier impressions by Levy (1945) and Jessner and Kaplan (1948), found that "the child of three years

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*"She" is used as the personal pronoun referring to children throughout this report because both children studied in the project were girls.

and under is the most susceptible to the circumstances surrounding hospital care," attributing most of the effect to separation anxiety. They noted, however, that they studied no children under two years of age. Schaffer and Callender studied the immediate and posthospitalization reactions of infants in the first year of life. They found a strict dividing point at seven months, under which hospitalization evoked little if any serious disturbance and above which it evoked disturbances similar to those of Prugh's two year olds. These authors suggested, therefore, that the vulnerable period for separation and hospitalization begins in the seventh month of life. Vernon, in his review (1965) and in his own research (1966), found that children from six months to four years, "in contrast to both infants and older children are especially vulnerable since they are both young enough to be dependent on their mothers and are old enough to recognize the mother's absence during hospitalization."

With the extensive knowledge now available concerning children's developmental tasks and vulnerabilities, we can step beyond basing our studies and practices on the

> child's chronological age, a factor which is inconclusive psychologically; or on the basis of the child's intellectual grasp of the situation, which is a one sided view diagnostically. Instead, (we) can think in terms of basic psychological differences between the mature and immature, and in terms of lines of development. The child's readiness to meet events such as . . . hospitalization. . . is seen then as the direct outcome of his developmental progress on all the lines which have a bearing on this specific experience. (A. Freud, 1965)

For our own purposes, then, we needed a grasp of what would be important to a 15 month old child: what lines of development would be occurring and which aspects of hospitalization might be most hazardous to her as a result? We would be able to fill in more details when we actually met her and the family. (In the following, I drew most heavily on *The Magic Years* by Fraiberg; *The Psychology of the Child* by Piaget and Inhelder; and *Clinical Aspects of Child Development* by Lewis.)

Increasing Neuromuscular Achievement and Integration

With the new freedom of walking, growing muscular strength, and increasingly adept coordination, the 15 month old is widening her horizons at a furious pace. She is trying out new physical skills, exploring the details of the house and yard, repeatedly returning to her parents for security and "refueling." But her sense of caution is not commensurate with her new capacity to create and encounter hazards, and as a result the parents need to place some restrictions on her activities and adventures. While firmly enforcing these safety measures, the parents still must not lose sight of the fact that

> body activity is a vital need for this age, and too many restrictions on motility create irritability, temper outbursts, and conflicts between baby and family which require much time to undo. (Fraiberg, p. 91)

This problem is not easily avoided in the hospital following surgery, when strict limitations on activity, in addition to sedation, are very commonly ordered.

Increasing Interpersonal Autonomy

As the child by this time has achieved a large degree of physical independence from the parents, she is also becoming more aware of her own separateness as an individual and is asserting, often most emphatically, her new found autonomy.

> He has his own rhythm, his own style, and often he seems to value his difference from his mother, his off-beat steps, as if they themselves were the signs of his individuality and uniqueness. To do just the opposite of what mother wants strikes him as being the very essence of his individuality. It's as if he establishes his independence, his separateness from his mother, by being opposite. (Fraiberg, p. 64)

Just as the parents have to both support and limit her increasing activities, they must support the separation and firmly enforce consistent limits on the child's poorly controlled impulses. She will cling dependently at times and attack aggressively at others. It requires confidence for the parents to stick to the limits when their child reacts hostilely to the enforcement. If they remain consistent, as well as emotionally supportive, the child gradually internalizes the controls, neither being too hard on herself and thus restricted and guilty, nor too easy on herself and thus impulsive beyond control. Hospitalization exacerbates the

difficulties of this already trying developmental task, often magnifying both her dependency and her aggressive impulses, while at the same time the parents may feel insecure in the hospital setting, and thus less confident and firm in their caregiving role.

Adapting to the Real World

A good proportion of the psychological energy driving the child in this stage can be directed into playing, manipulating, and learning about things in the world about. This will happen especially if the parents are helping her to invest her energy in it. She is discovering which objects are hard and which are soft, which make loud noises and which break when dropped, and so on. She is not yet at the point of using her toys and objects in symbolic play, so important to older children in preparing for and later integrating the stresses of hospitalization and surgery. But her play is still of vital importance, helping her to learn about the world around her at the same time as serving as an avenue for discharge of psychological tension. One aspect of this tension concerns the vicissitudes of aggressive energy which is of increasing interest during this time of life. It is believed that frustration of a certain level can heighten these energies and make such play even more important in its discharge function. If the frustration is too great, it may overwhelm the toddler, "leading to certain behavioral reactions.

that are often accompanied by the affects of rage and hate. The young infant may turn his aggression inward (e.g., head banging) or outward (e.g., temper tantrums, destructive behavior)." (Lewis, p. 59) Hospitalization obviously can be hazardous with respect to this developmental line, often increasing the level of frustration which can limit the possibilities for adaptive activities.

Capacity to Understand and Level of Object Constancy

The 15 month old child sees the world as revolving around her needs and interests. She has little capacity to put herself in someone else's place and to see their point of view. She therefore cannot comprehend what could possibly necessitate her being subjected to the intrusions and changes of a hospitalization. She does not distinguish the pains of illness from the pains of its treatment, and thus is intolerant of efforts to help her when they are painful or frightening. She is more likely to interpret hospitalization as punishment or abandonment by her parents. She has not yet become capable of preserving the memory of her parents in her mind when they leave, or at least it seems as if she soon gives up believing that they will return. Her "mental representation" of them is still shaky, but it can be reinforced by the presence of something that reminds her of them and of her home (transitional objects). Therefore, if separated from them in the hospital, she may come to feel

that they have left her at her time of greatest need with no justifiable reason, and that they may not be back.

Conception of Time

The question is often raised regarding the effect of longer and shorter lengths of time spent in the hospital on the psychological readjustment of the child when she returns home. Though clear differences can be seen between very brief as opposed to very long hospitalizations, the question cannot be answered without reference to the 15 month old child's limited intellectual concept of time and the way in which she experiences time.

> How the child will experience a given time period will depend therefore not on the actual duration, measured objectively by the adult, by the calendar, and by the clock, but on the subjective inner relations of either id or ego dominance over his functioning. It is these latter factors which will decide whether the intervals set for feeding, the absence of the mother, the duration of nursery attendance, of hospitalization, etc. will seem to the child short or long, tolerable or intolerable, and as a result prove harmless or harmful in their consequences. (Anna Freud, 1965, p. 61)

A short hospitalization marked by great inner turmoil could for example be more traumatic than a long hospitalization during which traumatic upsets are prevented.

2. What is the nature of the cleft palate defect and its treatment? What are its effects on psychological development and on the parent-child relationship?

When trying to anticipate the effects of hospitalization on an infant and parents, it is essential to understand the nature of the child's problem, the reason hospitalization is

required, the rationale for the different restrictions and procedures ordered, and the psychological and developmental disturbances in the child and parents likely to be associated with the problem. I intend in this section to provide a short explanation of the cleft palate defect that each of our patients had, the required treatment, (Lis, 1968) and the characteristic parental reactions to the birth and early care of children with cleft palates. (Tisza and Gumpertz, 1962).

A cleft palate is a congenital fissure in the median line of the palate, and may or may not be associated with a cleft lip. In our subjects, it was not. The cleft may be of any length from the uvula to the incisor foramen, and in our subjects it only went from the uvula (which was bifid) to the hard palate, but not including the hard palate. The isolated cleft of the soft palate presents three major difficulties. They all result from the fact that the child cannot make the usual soft tissue closure between the nasal and oral cavities, which requires an intact palate and intact pharyngeal muscles. This is called palatopharyngeal incompetence. The first problem to arise is around feeding. The cleft palate child, unable to create a closed chamber in her mouth, cannot suck and cannot prevent milk from running into the nose as well as back over the tongue and down the throat. A large soft flexible nipple with a large hole,

or else a syringe called a Breck feeder, is required for feeding. This serves the purpose perfectly well, although it requires much longer to take in the same amount of milk. The second problem due to palatopharyngeal incompetence is that milk and food can easily occlude the middle ear canal. Middle ear infections are frequent in these babies. Thirdly, because intelligible speech usually requires separation of the oral from the nasal cavity, cleft palate children often have trouble learning to speak. Many sounds are impossible to make, and the voice has a consistently hypernasal quality. She usually requires speech therapy even after palatal repair. Closely associated is an orthodontic problem; teeth emerge in incorrect positions.

It is not uncommon for other congenital defects to accompany the cleft palate. These can occur in any organ system, but are most common in the orofacial structures. A prevalent myth states that cleft palate children are likely to suffer intellectual impairment; this has been proven to be untrue.

Surgery is performed for two reasons: (1) to close the defect, and (2) to ensure palatopharyngeal closure. True success of the latter aim can only be evaluated by listening to early speech development. The surgery must be performed late enough so that sufficient tissue is available to make an effective closure, and so that the blood loss will not

represent too large a fraction of the total blood volume. This is generally safe between one and one and a half years of age and when the weight surpasses twenty pounds.

Nothing hard or sharp must enter the mouth for a few weeks following surgery. This includes fingers and hard crunchy foods. In addition, milk products encourage bacterial growth and dangerous infection on the suture site, and must be foregone for two weeks postoperatively. In addition, the surgeon in our cases explained that crying puts stress on palatal suture lines. He therefore directed the medical and nursing staff to prevent crying as much as possible for several days after surgery.

Mothers commonly feel hurt, disappointed, and helpless directly after giving birth to a child with a congenital defect. They acutely mourn the loss of the perfect baby they had imagined. Usually very soon though, the feelings of love and compassion overcome and suppress the painful emotions and the accompanying rejection disappears. Parents start wondering why it happened to them, what caused the malformation. Especially if there is no history of the defect in the family, mothers tend to "lend significance to superstitions and fears occurring during pregnancy." (Tisza and Gumpertz, 1962; see also Solnit, 1961) They may place the blame on medical procedures that were performed on them, or find the fault in their husbands, their mothers, or

something they themselves have done. The early feeding process, requiring so much patience on the mother's part and causing so much frustration on the child's, can lead to great tension and reduced body contact around the feeding experience.

After the first three or four months, usually the mother and baby are accustomed to the feeding process. The parents then begin worrying more about the coming orthodontic problems, the delayed speech and meager vocalizations, and the "ever present fear that the child whose head is damaged from the outside may be damaged from the inside too." (Tisza and Gumpertz, 1962) The latter concern seems to be the most persistent, resistant to repeated reassurances from pediatricians, surgeons, and psychologists that intellectual development can be expected to be unaffected.

The approach of the hospitalization brings the focus on the defect once again. The parents, who came early to consider negative feelings toward their baby to be unacceptable, may become extremely anxious. They often cannot express reasons for their anxiety, which in some parents, results from the intensification of their unconscious resentment of the child. Amidst this anxiety and ambivalence, supportive relationships to the parents may be the key factors in helping them to remain responsible as caregivers during hospitalization. In our project, it was crucial.

3. Are children of this age distressed during a brief hospitalization?

It can be seen daily on typical pediatric wards, and has been exhaustively reported in the literature, that very young children react with great distress to hospitalization. (Levy, 1945; Jessner and Kaplan, 1948; Prugh et al., 1953; Illingworth and Holt, 1955; Schaffer and Callender, 1959; Vernon, 1965, 1966; Robertson, 1970) The many different reports usually include the same types of reactions: constant plaintive crying, outbursts of screaming, hyperactivity and irritability alternating with underactivity and subdued withdrawal, thumb sucking, rocking, head banging, demanding and clinging behavior, fear of strangers, feeding disturbances, sleeping disorders, and in one case (Schaffer and Callender, 1959) a striking absence of vocalizations the first few days after admission (in children 7 - 12 months). In Prugh's study, the one most cited in subsequent literature, 50 children were studied on the ward before a new psychologically supportive program was implemented, and 50 others afterwards. Thirty-seven per cent of the supported and 50% of the unsupported children under three years of age displayed "severe" reactions, on a scale of "minimal," "moderate," and "severe." This percentage seems to be representative of other studies mentioned above. The impression is often that the child's limited defenses and inner resources are overwhelmed with stress, paralyzed, and

therefore are not available for adaptive purposes. Although Prugh's study was more than 20 years ago, few pediatric wards are much improved over the supportive one that he observed. (Robertson, 1970; Petrillo and Sanger, 1972)

It is important to realize that even in the absence of overt expressions of anxiety, anger, or withdrawal, the young child may still be in distress. Edith Jackson noted in 1942 that "good behavior in the hospital is not to be taken as absence of anxiety." (Jackson, p. 63) "This fact of crying in the presence, and apparent contentedness in the absence, of parents, is accepted on face value, with failure to take into account the power of a child's reserve about his innermost concerns." (p. 58) Sir James Spence, too, was suspicious of "contented" children: "their cheerfulness keeps on breaking through. But it is a deceptive cheerfulness." (Spence, 1947) In Prugh's study, some of the children most contented in the hospital were the most distressed at home afterwards. Robertson (1970) has pointed out that the upset that "contented" children show when their parents visit is the evidence of their hidden anxiety.

4. Are children and families distressed shortly following brief hospitalizations for young children?

There is considerable evidence of the difficulties, for child and parents, immediately following hospitalization, persisting for varying lengths of time. (Levy, 1945; Prugh et al., 1953; Schaffer and Callender, 1959; Vernon, 1966; Brain and MacLay, 1968; Robertson, 1970) Again, different

investigators find the same types of reactions among different very young children: increased dependency, clinging and demanding behavior, distrust of the parents when they leave even for a brief time, fears of the dark and of strangers, temper tantrums, hyperactivity, generally more aggressive behavior than before hospitalization, feeding disturbances, and sleeping disturbances as described in the hospital. In Prugh's study, the one week posthospitalization reactions, undifferentiated as to age between two and 12 years old, were reported as significant in 92% of the unsupported and 68% of the supported children. They comment that the youngest of the children showed the most reactions. After three months, this time including children two to four years old, 41% of the unsupported and 45% of the supported showed significant disturbances persisting from hospitalization. Again, this is representative of other investigators' findings.

5. Have long term psychological consequences of hospitalization during infancy been recognized?

There are numerous reports of long term psychological disturbances that seem to be due to hospitalizations in early childhood (Edelston, 1943; Faust, 1952; Jessner and Kaplan, 1948; Levy, 1945; Prugh, 1953; Robertson, 1970; Vaughan, 1957, and others) Edelston's cases were severely deprived in long term hospitalizations. Faust did not study hospitalizations in very early childhood. Prugh found infantile,

demanding behavior persisting for several months in a number of children under five years. Schaffer and Callender found that sleep disturbances could last up to 80 days in some children. Levy found night terrors extending over months and years after discharge. Robertson reported clinging behavior, tantrums, and aggression against the mother as well as other forms of insecure behavior lasting for days, weeks and longer after going home. In Vaughan's study, there were only four children under four years of age, but all four were still upset, in ways that had their onset at the time of hospitalization, after six months. Unfortunately, in these studies the data were usually found by infrequent, periodic interviews with the parents and not by close, regular followups that included actual observation of the children. But the number of findings strongly suggest that at least some children are significantly affected, in disturbing and long term ways, by hospitalization.

In some cases, the persistence of a psychic scar from hospitalization is more obvious or more carefully studied. Robertson observed and documented on film, the experience of Laura, a randomly chosen two year five month old girl in the hospital for eight days for a hernia repair. Her parents visited daily. She gradually lost interest in them, settling in to the hospital, as the days passed. When home, she displayed anxiety, irritability, demanding behavior,

separation anxiety, sleep problems, and hyper aggressiveness for a few weeks. Six months later she seemed to be relatively content and normal. But one day she burst out in anger at her mother, "where was you all that time?" (Robertson, 1970, pp. 20-27)

Another case of Robertson's was John, 17 months old. He spent nine days in a residential nursery, not a hospital, but like a hospital it did include an unfamiliar environment, a substitute caretaker for many children, and daily visits by the father. As noxious as the nursing environment was for John, the hospital included surgery, painful procedures, illness, restrictions of motion, and food deprivations. He deteriorated psychologically for nine days, and when his mother finally picked him up to go home, he would not look at her or respond to her. Three years later, as a four and one half year old, he was "a handsome, lively, little boy who gave much pleasure to his parents." But two features troubled the parents even then: (1) he feared losing his mother, and became very upset whenever she was not where he expected; and (2) every few months, seemingly out of the blue, he had bouts of provocative aggression toward his mother, lasting several days. They both seemed to have been legacies of the overwhelming trauma when he was 17 months old. (Robertson, J. and J., 1971, pp. 288-294) I will have occasion later in this chapter to discuss the relationship between this sort of separation experience and hospitalization.

This case study by Robertson raises tremendous methodological and conceptual difficulties facing all studies on the long term consequences of hospitalization. Escalona has pointed out that all attempts to establish a relationship between a single early antecedent experience and any later personality characteristic have failed. For one reason, global environmental antecedents such as "hospitalization" or "separation" are not truly the same environmental input in each case. "The evidence suggests that it is the interaction between numerous aspects of a particular social milieu and such intrinsic factors as age, endowment, previous experience, and inborn reaction tendencies that account for the variable consequences of any one aspect of experience." (Escalona, 1968, p. 13) This would suggest that an unimpeachable study of long term consequences would have to include detailed investigation of the various aspects of the social milieu, familiarity with as many of the particulars of the child's endowment and experience as possible, and actual observation of the interaction between the child and the environment. To be convinced of the connection between the hospitalization and personality characteristics much later would require such detailed studies, to be done at frequent intervals, before, during, and for a long period of time after hospitalization. To my knowledge, there has been no study even beginning to approach this level of depth and sophistication on the consequences of hospitalization,

either short or long term. That there are no ready and reliable statistics of this nature, however, is no cause for complacency. While careful research is still much needed, the accumulation of reports is highly suggestive that hospitalization can be damaging, and the destructiveness of weeks or months of family friction and child discontent is very important regardless of the poorly proven long term consequences. The requirement for statistically significant proof of the consequences of obviously destructive early childhood experiences has placed a major obstacle in the path of constructive improvement, in hospitals as well as other children's services.

6. What characterizes the children who seem most distressed by hospitalization?

Naturally, many factors come into play in addition to the nature of the stresses of illness and hospitalization in determining the responses of a particular child. Among these are characteristics of the child and family prior to admission: the developmental stage and therefore, stage-specific fears, anxieties, and strengths; ways of coping with stress that are characteristic of a given child, due to her endowment and experiences, particularly the experiences similar to hospitalization; the relationship between the child and parents, especially with the primary caregiver; and the way in which the parents prepare as hospitalization approaches. (Vernon, 1965; Prugh et al., 1953; Robertson, 1970, and many others.) Few studies have systematically

approached this issue, though observations of its importance abound. Brain and MacLay, in 1968, found the most distress among children emotionally disturbed prior to hospitalization, and children of mothers who very much wanted to come into the hospital and stay with their children but were too anxious to actually do it. Mason, reviewing literature in 1965, found a general trend that correlated distressed reactions with earlier emotional problems and poor family relations.

The most careful approach to the question was made by Prugh, in 1953. The correlations for those in the two to four year old group include:

(1) those with a prehospitalization limited capacity for adaptation to stress showed the greatest difficulty in adjusting to the ward milieu;

(2) and the same children had the most severe reactions to the total experience of hospitalization;

(3) some children who adjusted well in the hospital had the most crippling emotional reactions at home afterwards;

(4) having had previous hospitalizations seemed to be insignificant in predisposing the child to greater or lesser experience of distress;

(5) children who remained upset the longest after the hospitalization had been those who were most upset on the ward;

(6) children with relatively more unsatisfying relationships with the parents were the most upset.

Of all of these, the authors judged the relationship with the parents for the youngest children to be the "principal

determinant of the capacity of his ego to integrate conflicting forces from within and without."

This particular area of the literature seems particularly lacking in good evidence. The descriptions and speculations of prehospitalization characteristics and their relationship to the response to the experience are global. As a result, until more careful work is done on the issue, we can only conclude that probably, characteristics of the child-parent relationship and of the child herself are important in determining reactions to hospitalization, without commenting on which characteristics predispose to which kinds of difficulties.

7. Can a hospitalization be beneficial to a child and family? Which children?

There are three kinds of reports in the literature bearing on this question.

1. There are reports of experiences, without accompanying case reports or statistics, in which children have been benefited. (Langford, 1948, 1969; Jessner and Kaplan, Jessner, et al., 1952). Langford, in reviewing 25 years as a child psychiatrist working in liaison to a pediatric floor, wrote that "some children, if the experience is not too overwhelming, are able to deal successfully with the troublesome reactions released by the illness and hospitalization, to come out with renewed courage and vigor and to move ahead in life." Jessner et al. reported that "for a number of children, the T and A (tonsillectomy and

adenoidectomy) became a constructive experience, either as atonement for guilt feelings or as a challenge to their ego strength and a gain in prestige." These were older children than the ones in our study, but the principal of increasing the ego strength is still important for younger children. One particularly interesting report is by Bergman (as described by Anna Freud, 1952): "certain ego skills, speech, etc., may undergo an accelerated development to compensate for motor restriction of one limb."

2. In some studies of psychological impact of hospitalization, in which benefit as well as detriment is included in the behavioral rating scales, a few children have shown benefit, behaviorally. (Prugh, et al. 1953; Vernon and Schulman, 1964; Vernon, 1966. See Vernon, 1965, for some others.) In 25% of the cases studied by Vernon, through questionnaires to the parents after hospitalization, improved behavior was indicated over that prior to hospitalization. He did not know what characterized these children. In Prugh's study, five of the 50 who made up the experimental, well supported group, were described at discharge as improved psychologically. No common characteristics could be seen among the voluminous coded information of the study, but careful scrutiny led Prugh to think that what was called improvement was that all five children had "inhibited behavior previously unacceptable to their parents." In these types of studies, it is very difficult to know what the reports of

behavioral improvement by the parents really mean.

3. There have been a few cases in which the hospitalization was conceived from the start as a therapeutic treatment modality psychologically as well as physically. (Solnit, 1960; Ferholt and Provence, 1976) These may be cases in which the child is removed from a depriving or traumatic home environment, away from the parents (Ferholt and Provence, 1976), or in which parent and child were admitted together in order to strengthen their bond and to help the mother become more effective. (Solnit, 1960; Prugh, in Shore, 1967) Prugh, in "Planning for Children in the Hospital," (Shore, 1967) especially noted the therapeutic effects for "infants and children with various kinds of psychosomatic problems including some feeding difficulties, diarrhea, vomiting, marked toilet training problems, failure to thrive, and rumination." It is presumed that in many of these cases, the mere change from the depriving home environment to the perhaps more responsive (if well handled) hospital environment is the therapeutic factor. In fact, the case described by Ferholt and Provence was a 10 month old boy with failure to thrive and psychophysiological vomiting, and one of Solnit's two reported cases was another failure to thrive. The careful studies in each of these cases showed the benefit of a skillfully managed hospitalization. Ferholt and Provence's extremely careful diagnostic investigation, formulation, and detailed psychological treatment plan, which

we will be returning to, exemplifies a new level of sophistication in applying resources of the pediatric ward to psychosomatic problems of infancy.

This author concludes from reviewing this aspect of the literature that the only cases which have been proven to benefit from hospitalization are those in which the child was either deprived or traumatized to begin with. This leaves open the question of whether relatively normal children can be shown to benefit. There are suggestions that it may be possible, but the investigative methods of the relevant studies have not been sufficiently precise to show meaningful benefit. One of the tenets of this thesis is that such benefit, seen in the context of normal development, is possible. As Solnit wrote, "when the crisis of hospitalization is integrated as an important experience by the mother and child, one can speak of crisis being used to further development."

8. Which factors in hospitalizations seem to be the most stressful?

When a 15 month old child enters the hospital, she is faced not with one stress, "hospitalization," but a multitude of intrusions, changes, and deprivations. It is no problem to list what many of these are--the literature is filled with such descriptions. What is difficult is to separate them out as individual factors and to weigh them according to their degree of importance as stresses. Prugh wrote that "the diffuse quality of much of the stress

involved, the wide variations in types of medical and surgical procedures employed, and other factors made conclusions difficult in regard to the effect of particular types of stressful experiences." (p. 82) Except for the study of separation, which we shall review, there have been no reports of pure studies of other factors, uncomplicated by several stresses occurring during the same experience. Of course, different aspects of hospitalization take on different significance depending on a child's developmental level and individual character. But for our purposes it was valuable to accumulate others' experiences and speculations of what the stressful factors are.

(1) <u>Admission</u>

Many reports have commented upon the difficulty of admission to the hospital for children and parents. None has put it so eloquently as Grover Powers whose words, although he said them 28 years ago, can be seen on some occasions, and a little bit on most occasions, to still be disturbingly accurate.

> The process by which children are admitted into an emergency room or a ward of a hospital is often a formidable and barbarous performance; the procedure is too often thoughtlessly and unnecessarily cruel. Neither parent nor child is prepared by any one for what is to take place; little or no care is exercised as to the frightening sights the child will (but need not) witness or the terrifying words and sounds he will (but need not) hear before he is taken, against his wishes, from the security of the family group into the great unknown of the hospital ward. The proceedings, even if they do not

> 'break' the child's 'heart immediately,' are traumatizing to all unhardened witnesses, be they orderlies, nurses, students, members of the house staff or attending physicians, to say nothing of parents, whose only resource in frantic efforts to comfort the terrified victim is too often one lie after another. (Powers, 1948, p. 374)
>
> I regard parents who are going through the process of having their sick child admitted to an institution as emotionally ill themselves and treat them so. The prolonged waiting periods which they are obliged to undergo, the admitting red tape and the contacting and talking with numerous physicians, nurses and clinical clerks are causes of pain and anguish and warrant just criticism.' (Powers, pp. 374-375)

The case in my Preface and the first case in our project demonstrated to me the continuing relevance of these words.

(2) Strange Environment, Unknown Adults, Change in Schedule

Again with this factor, many have commented on it. (Bakwin, 1951; Powers, 1948; Prugh et al., 1953; Freud, 1952; Langford, 1961, and many others) It has been put most completely and understandably by Robertson (1971, p. 301).

> But for the young child a strange institutional environment is a multitude of harsh experiences, deprivations, and demands, which place a great burden on him. He will be offered strange foods, strange implements with which to eat. He may be helped too much, or too little. The noise and movement during mealtimes are likely to impose strain.
>
> His toiletting will be fitted into the institution's routine, not geared to his particular rhythm as happens at home. His special signs or calls will probably not be seen or heard. . .
>
> The child used to sleeping for several hours in the morning and having a late lunch may find himself too tired to eat lunch, wakeful when

> others sleep, and ready for sleep just as the rest wake up. His sleeping rhythm will be disturbed.

What this, as well as other investigations, reflects is an understanding that a stress in and of itself is the hospital environment--its routines, atmosphere, and physical characteristics regardless of the presence or absence of separation, surgery, limitation of motion, and so on. The child at home has developed a number of rhythms, of eating, of sleeping, of activity. She is used to a certain amount of and kind of social stimulation. Her whole world has been a certain physical, social, and affective environment which by this time she more or less "fits." To understand the degree to which this is a change and therefore a stress, one would have to make very detailed systematized observations, of the kind done by Escalona, for instance, of the nature and amount of social inputs and outputs, and so on, without and within the hospital setting.

(3) Procedures

Prugh reported that the youngest children reacted to physical and medical procedures as if they were hostile attacks, with wild, aggressive behavior and at times, panic. A "temporary paralysis of ego functions resulted." The objective threatening quality of the procedure seemed to have nothing to do with the degree of reaction. Anna Freud (1952) explains this by noting that for infants and young toddlers, pain and anxiety are intimately connected. She says, as a result, that for the older infant, the pain of

injections and innoculations may be no more and no less distressing than other less objectively painful experiences. One interpretation, offered by Levy in 1945, and perhaps most true of older children, is that the enormous reaction to some small procedures represents a displacement of anxiety more appropriately connected to other aspects of the hospitalization. What is important to us is that small procedures are no small matter for the young toddler; she seems to fear annihilation or attack and can easily be overwhelmed and paralyzed emotionally by what we adults feel is harmless.

(4) Surgery

Although there is widespread agreement in the literature that surgery is traumatic or potentially so to the psyche of the young child, most discussion of it focuses on the anxiety about it as it approaches, and the postoperative psychological reactions that have been seen. (Langford, 1961; Levy, 1945; Pearson, 1945; Jessner et al., 1952; Freud, 1952) The 15 month old child does not conceptually anticipate surgery (although she no doubt reacts to the anxiety of those around her, through a process of "contagion") and the postoperative reactions reported suffered from the problem spoken of earlier--the inability to sort out its role individually as a stressful factor. Freud claims that surgery releases anxiety that then must be dealt with by the ego. In any case, there is no doubt that "surgery" as a whole experience, including anesthesia, and then waking up

bloodied (in cleft palate surgery, the mouth oozes blood afterwards), restricted, in a strange environment, and so on, is traumatic at 15 months of age, as it is at any age.

(5) Restriction of Motion

The authors who have dealt with this as a separate stress comment mostly on the role of activity in discharging built up aggressive tension and the effect of restricting activity in the youngest children being to increase that tension, frustrating its discharge, "overeroticizing the whole body" (Freud, 1952, quoting Greenacre), and possibly overwhelming the child with anxiety. (Langford, 1961; Freud, 1952, and Prugh, 1953)

(6) Deprivation of Food

It is agreed that deprivation of food is an important stress for a child of 15 months. Two points can be made. For one thing, as Freud emphasizes (1952), food for the young child is invested with as much emotional as nutritional significance. Withholding of food can be felt as rejection and loss of love. Secondly, the tension created around the frustrated oral desires can distract from the use of more advanced and adaptive ego functions to deal with the other stresses being faced at the same time. It is interesting and significant for the very young child, that confinement (restriction of motion), inflicting of pain (spankings, procedures), and deprivation of food have been used as punishments through the ages, and without proper understanding of

their justification in the hospital, are experienced as such by many young children. (Freud, 1952; Langford, 1961)

(7) Parental Anxieties

Prugh (1953) was the first to make a point of studying the parents as well as the child during hospitalization, though as he mentions, many had noticed the importance before him of the parental anxieties in affecting the child. He noted that a child's behavioral disturbances could reflect the parents' difficulties in handling their realistic fear, their guilt over possible causation of the illness, or hostile feelings toward the child. If there was too much anxiety, participation in ward care was blocked. "A small number in each group could not bring themselves to visit at all because of anxiety or guilt."

Many since Prugh have commented on the same problem. Some studies have concerned themselves primarily with parents (Skipper, et al. and McCollum). Skipper et al. found that for many parents, surgery for a child was an extremely anxiety provoking experience. Freud tried to explain how it is that the anxiety of the parents gets communicated to the child. She stressed that the parents, in coping with their feelings, may change their way of handling the child, for instance, either over- or under-indulging. "The child, on the other hand, reacts to such unexpected handling as to traumatic experiences, feels bewildered by the upsetting of

formerly immovable emotional and moral standards or finds himself unable to renounce the incidental emotional gains after recovery."

Solnit was attempting to strengthen the mother-child bonds during hospitalization, and therefore made observations that were particularly pertinent to our project:

> When a child under the age of two is hospitalized, the mother may be overwhelmed by her feelings of helplessness and guilt, whereas the child is overwhelmed by his anxiety and depression at feeling abandoned, hurt, and hopeless. Even in a brief hospitalization, the mother's guilt and feelings of helplessness may have a deleterious effect on the child's capacity to recover from the psychological demands of the hospital experience. (Solnit, 1960, p.46)

(8) Separation

The most controversial and often discussed stressful aspect of hospitalization is separation of the child from her parents. The controversy has centered around the question of what constitutes the most important aspect in the trauma of separation. Is it the absence of the particular primary object, usually the mother, regardless of the quality of substitute care, as Edelston, Spitz, and more recently, Bowlby (1969, p. 26, 29) have implied? Or is it the absence of good quality continuous substitute "mothering," that is most destructive, as Howells (1963), Branstetter (1969), and Robertsons (1971, 1972) have claimed? Most influential in posing the question was Yarrow (1961), who in

an excellent review of separation, pointed to the fact that when studied, separation was always accompanied by changes for the child in the physical, affective, and social environments. He suggested a view of separation more balanced in relation to the distressing aspects usually surrounding it, at least until more "pure" studies were done. One of the earliest investigators to take a firm stand in opposition to Bowlby was Howells, in 1963: "The view expressed here is that the circumstances attending the separation are the most important factor in determining whether or not the child is deprived of the right care rather than the separation itself."

Branstetter produced some evidence on the matter in 1969, in studying the hospitalization reactions of 30 toddlers, 10 of whom received typical hospital care with no single continuous caretaker, 10 of whom received good quality substitute care from a single person, and the other 10 of whom were attended continuously by their mothers. "The substitute mothering group showed behavior similar to that of the mother-present group. These two groups manifested much less disturbed behavior than did the mother-absent group." (Branstetter, 1969)

Also contradicting the view that separation from the mother is in all cases traumatic are the cases, referred to earlier (Ferholt and Provence, 1976; Prugh,), in which

the child was actually benefited by removal from the mother and home. This would suggest that we must look closely at the quality of the mother-infant relationship. This could help us to know in which cases separation was really the best thing for the child, in which cases the mother could best handle most of the hospitalization with her child by herself, and in which cases a certain combination of mother and staff would be best in providing the important caretaking functions.

James and Joyce Robertson reported in 1971 on studies of their attempting to "create a separation situation from which many of the factors that complicate institutional studies were eliminated; and in which the emotional needs of the children would be met as far as possible by a fully available substitute mother." Four young children in this situation, in 10 to 27 day separations, did not respond with the acute distress and despair described in the literature. (James Robertson had described, in 1952 and in 1970, three phases of response to virtually all separations in early life: protest, despair, and denial/detachment, seen as stages leading to the settling in as a superficially contented child in the hospital.)

"Because they were not overwhelmed, as children admitted to institutions commonly are, their inner resources were available to cope with the loss of the mother." "The relationship with the foster mother then held these children

in a state of manageable anxiety." "Although under considerable strain throughout, all four children cared for in our supportive foster situation functioned and related well, learned new skills and new words, and at reunion greeted their mothers warmly. The separations had not been traumatic. The children had not been overwhelmed." That separation was still a strain could be seen in the careful observations and films that the Robertsons made, and because in the case of a 17 month old, Jane, it was "several weeks before there was a lessening of the provocation toward her mother."

The Robertsons emerged from this study with a more balanced view of what separation means to the child. The mother "helps to mediate the environment." (Murphy, 1964, quoted by Robertsons, 1971) Without the mother, the child is totally exposed to the impingement of the strange environment. Separation responses will differ depending on a variety of factors, some in the child's favor and some against her. (See chart of factors, p. 310.) For instance, they wrote of John, a 17 month old who was denied adequate substitute mothering for nine days in a residential nursery while his mother was in the hospital. "The balance between stress and support operated against John. His immature ego was overwhelmed and trauma resulted."

The "pure" situation created by the Robertsons is obviously one that cannot be duplicated in the hospital,

where the medical necessities constitute inevitable additional stresses. But the way of thinking that they evolved is most useful to us (see underlinings in above quotations). They conceive of the young child as an active person possessing some inner resources for coping with stress in an adaptive, constructive manner. Because of the immaturity of ego development, however, she is still dependent upon adults to effectively mediate the environment. The parents are likely to be well capable of doing this, because they are most familiar with her subtle non-verbal cues, the meaning of her cries and vocalizations, and her usual patterns and rhythms of sleeping, eating, playing, etc. But if necessary, other adults can serve as the buffer, helping her to hold her anxiety in a manageable state. To do this, they need to know her habits and patterns and how to "read" her messages. If supported and not overwhelmed, the child can use her own resources to adapt, hopefully then growing in confidence by personally mastering the situation.

A balanced view of the different aspects of separation still cannot afford to underestimate the importance of the mother-infant bond itself. The mother's various functions can be more or less adequately replaced; the mother herself, as the child's particular primary object, cannot. Bowlby, Freud, and Robertson are in agreement that once the primary attachment is made, a significant rupture in it will result

in a painful experience which can be exacerbated by simultaneous stressful factors or mitigated by supportive ones.

In the hospital, it is important to remember that a parent, even if physically present throughout, may, due to his/her own rising and falling anxieties, at times be emotionally unavailable to the child. In those cases, it is necessary to respond as if a partial or total separation has occurred, providing emotional support for both parent and child. This was crucial to understand in the performance of our project.

9. What has been and can be done to minimize traumatic possibilities and maximize beneficial possibilities of hospitalization?

Separating out and weighing various psychologically prophylactic measures according to their effectiveness proved as difficult as weighing stressful factors according to degrees of stressfulness. Prugh et al. were trying to assess such measures, and concluded that it "is impossible to distinguish the most effective components of the preventive program. . . the more diffusely supportive aspects of the program were most prophylactic in effect." (Prugh, et al. 1953, p. 102). However, the literature still has presented us with an encyclopedia of possibilities to make hospitalization less traumatic and more beneficial. Many of the studies are descriptions and impressions of modifications that have been made in hospitals (Spence, 1947; Powers, 1948; Jackson, 1942; Pickerill and Pickerill, 1946; James

and Wheeler, 1969; Prugh, 1953; Illingworth and Holt, 1955; Faust, 1952; Plank, 1971; Petrillo and Sanger, 1972). Others report the results of comparative studies in which some children do and others do not receive certain changes in hospital treatment (Fagin, 1966; Branstetter, 1969; Prugh, 1953; Vaughan, 1957; Brain and MacLay, 1968). Still others organize their clinical observations and the literature in order to make recommendations (Yarrow, 1964; Vernon et al., 1965; Mason, 1965; Robertson, 1970; Lewis, 1971). A few describe in more detail cases in which attempts were made to individualize a management plan to meet the needs of particular children and families (Ferholt and Provence, 1976; Solnit, 1960; Robertson, 1956; Petrillo and Sanger, 1972). In presenting this part of the review, I will follow closely the organization in the previous section on stresses of hospitalization, suggesting the recommendations made to make each one more manageable for child and parents.

(1) Preparation

> Preparation is an adaptive process in which an individual mobilizes inner and external resources for the mastery of an anticipated experience. When the experience is stressful in nature, preparation serves a crucial purpose: To the degree that a person can, prior to the experience, recognize, express, and resolve the feelings that are stimulated by the stress, he may avert being psychologically overwhelmed by the experience. (McCollum, 1967)

This seems to be the impression of most of the authors who have commented on preparation for hospitalization and surgery. Unfortunately for our project, almost all efforts have been

directed to older children, who can both play out and verbalize their questions, fears, and fantasies. For them, its value has been seen repeatedly. (Robertson, 1970; Plank; Vaughan; Petrillo and Sanger, just to name a few).

Many have pointed out that because of the parents' important role, especially in relation to the younger children, preparation for them is of critical importance. (Powers, McCollum, Solnit, Belmont, Robertson) Most of the principles used in preparing the parents are the same as those for children applied in different ways depending on the age, and have been represented by different authors as follows:

1. A realistic understanding of the disorder.
2. Comprehension of the purpose of hospitalization.
3. Understanding of the nature of intended diagnostic and therapeutic procedures.
4. Knowledge of ward routine.
5. An awareness of the affects that are stimulated by the impending hospitalization and a capacity to manage them. (1-5 from McCollum)
6. Beginning alliance between parents and staff, and familiarity of child with staff. (Robertson, 1970; Vernon, Belmont)
7. Change in routines towards what must be performed on hospital ward. (Powers, Plank, Petrillo and Sanger)
8. Preadmission visit to the ward. (Robertson, among many others)
9. Use of leaflets, books, etc. to prepare parents and child. (Plank, Robertson, Petrillo and Sanger, and many others)

> 10. Robertson warns in particular that three aspects of preparing the parents is often left out: (a) caution them that the young child may be very unhappy and that many other crying children may be on the ward; (b) tell them that there may be much pain after surgery; and (c) caution them that on return home the child will be difficult in his behavior. (Robertson, 1970, p. 74)

There seems to be much doubt as to whether the presymbolic child can be prepared in these ways. Mason (1965) says that this is true and that it is due to the inability to understand what is to happen. Robertson (1970) says that preparation for very young children is impossible (p. 72) and preadmission visits to the ward worthless for the child under four or five years old (p. 71). So when we tried it in our project, we were without many recommendations from the literature about how to proceed.

(2) Admission

Just as admission can be the horrendous and ominous beginning for parents and child (see Powers in previous section), it can also be the first important step in developing a constructive patient-parents-staff alliance. Skipper et al. studied explicity the value of a special effort made at admission. They showed that an extra five to ten minutes of special contact at that time with the mother, explaining procedures and schedules and expected reactions of the child, as well as allowing for questions and the voicing of worries or uncertainties, resulted in

lower levels of stress and greater adaptation to the hospital than in the mothers without extra attention.

Many investigators have observed the positive effects of the parents accompanying their child to the bedroom at admission, and staying there to put her to bed like at home. (Levy, 1945; Powers, 1948; Illingworth and Holt, 1955; Prugh, 1953) Robertson stressed also that this is a chance when the mother and child can get to know the special nurse assigned to them. The staff person gets a chance to learn more about the child's particular habits, patterns, likes and dislikes, and about the mother-child relationship, both by interviewing and by observing.

(3) Surgery

The actual stress of surgery itself is impossible to avoid, but the procedures surrounding it are subject to various approaches, as are the ways in which parents are handled during the operation. Levy (1945) was one of the first to suggest that the parents be there when the child goes to sleep and when she wakes up, that the child be sedated prior to anesthesia, and that she wake up in the same room she went to sleep in. These measures would minimize the number of additional changes she would have to cope with. Skipper et al. found that many mothers suffer intense distress just before, during, and just after the child's surgery, and that "the level of the mother's anxiety

can be reduced through social interaction with an authoritative person who provides information and emotional support." (p. 501)

(4) <u>Strange Environment, Unknown Adults, Change in Schedule</u>

The basic principle here is simply to make the environment more familiar and secure, make the adults better known, and minimize the necessary changes in schedule. The application of these ideas will vary from one case to another, but several possibilities are suggested in the literature.

First of all, the number of people coming in contact with the child can be reduced to what is necessary even though this is complicated by the provision of care in research and teaching settings. The parents can be informed of who each person is by name and by function, and even given a written list. All people working with the child can make efforts to become more familiar through some non-directed play in the secure presence of the parents. Especially for very young children, the number of part time people, such as volunteers, should be held to a minimum.

Secondly, a child can have one nurse in charge of her care, someone with whom she has grown familiar on a preadmission visit and on admission. This nurse can be most familiar with the parents, with the home environment through talking with them, with the child's routines and preferences. Robertson has discussed this most extensively, and pointed out how it can only occur within the context of

the "case assignment" system of nursing. In this system, each nurse is responsible for a certain number of patients and their families. In the "work assignment" system, each nurse performs a certain set of duties upon every child, thus coming to know no one of them very well. Finally, in the "team assignment" system, the children are divided into groups, and one team of nurses works with each group. Case assignment nursing can be more demanding emotionally on a nurse, as the involvements with the sick children and their parents are more intensive, and it may require a larger staff, but it is undoubtedly better for very young children and it is potentially more rewarding for a nurse.

Thirdly, a child can bring from home some of her own toys, clothes, important possessions, and especially "transitional objects." (Robertson, 1970; Mason, 1965; Bakwin, 1942; Powers, 1948)

As with many of the recommendations we find, the key behind their implementation is the attitude of the staff toward them. It is only when they believe that minimizing the stresses in moving from home to hospital are important that they can commit themselves to the necessary modifications.

(5) Procedures

As discussed before, procedures can be overwhelming and traumatic for a young child, at times used as focal points upon which to concentrate stores of diffuse anxiety.

Powers called for special attention to this: "A little time spent in getting acquainted often saves later delay and pain and may prevent the development of antagonisms to physicians exhibited by many adolescent and adult patients. Procedures tend to become routinized in hospitals, because of fear of significant omissions. . . it is wise to challenge continually all routine procedures and examinations and the ways they are carried out, to insure that they are performed, not for their own sake, but really to help the patient and to advance the knowledge of disease." (Powers, 1948, p. 377. Robertson expresses a close agreement with this on p. 79).

Several very specific suggestions have been made:

(1) avoid scheduling procedures near feeding, nap, or special activity times. (Prugh et al., 1953)

(2) keep parenteral medications, requiring needles, to a minimum. (Belmont, 1963)

(3) do procedures in a special room, not in the child's room, and comfort the child afterwards. (Bakwin, 1953)

(4) the mother or special nurse should be present at any painful or frightening procedure. (Robertson, 1970, p. 79)

(6) Food Restrictions

This is often a necessary part of hospitalization and in itself can hardly be remedied for the 15 month old who cannot understand why she must forego eating. One can only try to keep the diet modifications, just as in the case of procedures, to a minimum. (Belmont, 1963)

(7) Restrictions of Movement

It was pointed out earlier how difficult this can be for toddlers, for whom the employment of rapidly developing neuromuscular capacities seems to be a compelling need. Belmont (1963) suggests a careful continuing evaluation to assure a necessary minimum of confinement. Solnit (1960) recommended that the parent help the child to invest in appropriate toys. Prugh (1953) suggested selected, adapted play opportunities depending on the particular limitations. Levy (1945) recognized the need of the post-surgical restricted child for maximum possible use of distracting play, muscular activity, and movement around the ward. Freud (1952) cited Thesi Bergmann's (1945) observations that the restraint of limbs, blocking a motor discharge system, may in compensation accelerate the development of certain ego skills, speech, etc. This implies a helpful recommendation of encouraging the use and development of the compensatory functions during restrictions of movement.

(8) Parental Anxieties

Some means to help the parents cope have already been covered: preadmission contact, special attention during admissiom, and continuing support in their roles as caregivers either during visits or when rooming in. "The mother is not replaced by the nursing and medical staff. On the contrary, the nursing and medical staff help the mother to cope with the problem at hand." (Solnit, 1960) This, of

course, will depend on the parents' capacities; a full time or part time substitute caregiver may be indicated.

(9) Separation

The stress of separation itself may be the most difficult to counter. All other stresses considered are magnified in their impact without the presence of the mediating caregiver. A continuous and highly personalized single caregiver, skillful and concerned, may still not be good enough (Robertsons, 1971). In any case, that is what would be indicated. As another tactic, many authors suggest, and most hospitals have provided, liberal and flexible visiting regulations. (Illingworth and Holt, 1955; Bakwin, 1942; Powers, 1948; Edelston, 1942; and many others) Rooming in is strongly supported by many studies and clinical impressions. (Fagin, 1966; Brain and MacLay, 1969; Spence, 1947; Pickerill and Pickerill, 1969; James and Wheeler, 1969; Illingworth and Holt, 1955; Robertson, 1970; and many others) Unaccommodating physical facilities has provided a major obstacle to many parents wishing to room in on many hospital wards. In 1968, only 28 of 5,000 general hospitals in the United States had facilities allowing parents to spend the night with their child. (Hardgrove and Dawson, 1972)

(10) Preparation for Home

Robertson (1970, p. 77) in particular has drawn attention to this factor. He is especially interested in the transition of hospital-to-home for the rooming-in mother and

child, but the arguments he makes apply to parents who only visit as well. "Mother will take over a child whose diet and other requirements she understands because she has participated in their preparation. She will not be faced by new and perhaps unfamiliar demands on her competence."

(11) Developing a Coherent Approach

It is disconcerting that even when extensive prophylactic measures have been taken, careful investigators find that the younger children benefit the least. (Prugh, et al., Illingworth and Holt, Vaugh, Plank) Although this may partially represent an insurmountable fact of life, it may also partially reflect Robertson's observation, quoted in the beginning of this chapter, that even with many improvements, we still may lack a "coherent approach to meeting the child's needs." As I interpret that, it means that we need more than a variety of improvements to minimize stress, prophylactic measures applied in all cases. We need to individualize our approach to each particular child in developing a hospitalization plan that reflects not only a concern for minimizing trauma, but also a concern for maximizing the possible benefit. Although case studies can be found throughout the literature (Edelston, 1943; Petrillo and Sanger, 1972; Solnit, 1960;

Robertson, 1970, and many more), none is so relevant to our case as that described by Ferholt and Provence (1976). Their case was a 10 month old with vomiting and growth failure, which were due to marked deficits in the mother's ability to provide good nurturance, and thus hospitalization, away from the mother, meant something very different than for a child undergoing a routine surgical procedure. But the principles followed in the case are highly applicable to our attempt to create a beneficial, growth-promoting hospitalization.

First, prior to admission, they began to assemble a detailed profile of the child, including the developmental status and history in several areas of functioning, the nature of interaction with the mother, the child's current psychological situation, and the effects of various environmental factors on him. This, for instance, included spelling out what made the child most uncomfortable, most relaxed, most quiet, and most attentive. A profile along lines such as these would be possible in routine hospitalization, attainable during a preadmission contact and at admission interviews and observations. Such detail might not be possible, but an abbreviated assessment of similar areas of functioning as Ferholt and Provence's would be practicable.

Secondly, the formulation they arrived at based on interviews and observation was used to develop the treatment plan (unlike most pediatric cases, in which the developmental data are not reflected in the treatment plan or usually anywhere else in the chart except the initial history). This was addressed to the child's personality, situation, and developmental needs. It filled in the blanks of the well intended but often worthless TLC recommendation that depends on "intuitive sensitivity and skill of a particular caregiver." The treatment plan tried to minimize the stressful experiences, maximize the pleasurable ones, and later to challenge the child to a manageable and constructive degree in a "curriculum of play."

Thirdly, the plan, because it necessitated staff commitments and highly personal involvements, required close collaboration among the staff, including the working out of disagreements and strong feelings. It brings out the difficulty of changing to a new treatment plan as well as the personal commitments required to give humane, sophisticated, sensitive care.

Finally, the treatment plan required careful observation and recording by the nurse. This is something usually done attentively concerning medications or intakes and outputs, but rarely with any detail or regularity concerning the behaviors which affect the child's psychological status.

So, in this review I have outlined the kinds of questions we were asking, and the answers, sometimes unconvincing but highly suggestive, that others claim to have found. It helps to provide a framework, a background, but serves only as a beginning to what was for many of us, a highly moving and significant event.

SUMMARY

Introduction

1. There is considerable agreement that our usual pediatric hospital care does not adequately reflect the lessons we have learned about the psychological impact of hospitalization on young children.

2. In this project, we attempted to formulate lessons from the literature, from our experiences, and from a careful case study, into a detailed psychological treatment plan for a 15 month old girl undergoing cleft palate surgery, then to implement that treatment plant with intentions of providing the most benefifical experience we could.

Historical Perspective

3. A brief historical sketch demonstrates that children's hospitals are a relatively recent phenomenon in our culture, and that significant interest in the psychological impact of hospitalization on children dates from the 1940s.

Literature Review

4. It has been demonstrated that the most vulnerable age during which to be hospitalized, as regards the psychological impact, is between seven months and four years, because of the great dependency characteristic of that time and the sensitivity to separation from parents.

5. We now can formulate the vulnerability to hospitalization more usefully in terms of developmental tasks of a particular child rather than in terms of age.

6. A developmental picture of a 15 month old is drawn, relevant to our attempted "beneficial" hospitalization of a 15 month old girl.

7. Evidence shows convincingly that very young children react with great distress to hospitalization, with increased dependency, clinging behavior, inwardly and outwardly directed aggression, and feeding and sleeping disturbances. It is important to realize that even in the absence of overt expressions of anxiety, anger, or withdrawal, the young child may still be in distress.

8. Considerable evidence demonstrates that young children continue to be upset in the home for varying periods of time, up to several months after discharge. Most of these reactions can be categorized in general as Separation Anxiety, Aggression, and Eating and Sleeping disturbances.

9. While no study has convincingly demonstrated, in a statistical manner, long term detrimental developmental consequences of hospitalization in early life, the accumulation of case reports and suggestive studies leaves no doubt that it can indeed be damaging. Regardless of the nature of poorly understood long term sequelae, the weeks and months

of family friction due to short term hospitalization can be devastating.

10. Evidence suggests that young children with psychological difficulties and those with unsatisfying relationships with their parents are more likely than other children to suffer trauma from hospitalization. It is suspected that some other important factors include: the nature of the illness, the nature of required treatment, the child's developmental stage, the child's particular ways of coping with stress, and the way in which the parents prepare themselves and the child for hospitalization.

11. It has been convincingly shown that children already deprived, as well as being the most vulnerable to hospitalization, can be benefited by it if carefully managed with specific attention to the needs and characteristics of child and parent. Studies are suggestive that relatively normal children and families can also benefit from the experience, but evidence in the literature at this point is weak and inconclusive.

12. The following aspects of hospitalization have been shown to be stressful for a young child and family: Admission; Strange Environment, Unknown Adults, Change in Schedule; Frightening and Painful Procedures; Surgery and the Immediate Postoperative period; Restriction of Motion; Deprivation of Food; Parental Anxieties as Affecting the Child; Separation of the Child from the Parents.

13. Many recommendations have been made in the literature of how to help the child and parents cope with the potentially traumatic stresses listed above. The chapter includes discussion of many of them.

14. Most importantly lacking now in many pediatric ward programs is a coherent approach which makes use of many of the above recommendations in an individualized treatment plan designed to meet the needs of a particular child and family. One example is discussed in which this was done thorough and documented in detail.

APPENDIX: PART TWO

INTERVIEW WITH PARENTS

I. Description of home setting.

  A. Neighborhood. Physical description of house. General atmosphere: noisy? friendly? teasing? joking? solemn? relaxed? fighting and tense? Neatly kept versus cluttered. Who lives and spends time there?

II. Description of Parents and child and initial impressions.

III. Parents' view of the project.

IV. Parents' past experiences with child in the hospital and/or visits to doctor.

V. Parents' general attitudes about hospitals, doctors, and illness.

VI. Family data.

  A. Parents' ages, educations, occupations, geographical background, cultural and religious background.
  B. Financial status, including method to finance hospitalization.
  C. Length of time married, number of children, number of moves from house to house since child was born.
  D. Parents' relationship to their own parents; to friends.
  E. Parents' plans for family size. How did child (our subject) fit into these plans? Was this child planned?
  F. Parents' expectations of child for the future (e.g., what do you think and what do you hope, he/she will be doing in twenty years?).
  G. Parents' health histories: physical health, mental illness, congenital defects, major illnesses, pregnancies.

VII. Pregnancy, labor, delivery. Maternal and paternal attitudes toward pregnancy, labor, birth, sex of child, congenital defect.

VIII. Neonatal period: parents' reactions to baby, who he/she was like, what kind of personality he/she had.

IX. Child's health history.

A. Growth and Development

1. Growth curve, when rolled over, sat unsupported, pulled self to standing, stood, walked holding furniture, walked, could kick. When imitated speech sounds, said words? What words? When was shy of strangers, attached to mother?

B. Eating history

1. How was he/she fed at first? When was a cup used? When solid food? Any feeding problems? Much vomiting in past?

C. Sleeping history

1. When could he/she sleep through the night? Has he/she slept alone? in parents' room? in parents' bed?

D. Separations: ages when they took place, duration of separation, surrounding conditions, substitute care, reactions of child, of parents.

E. Accidents, allergies, immunizations, illnesses.

X. Present Status

A. Eating: schedule, food preferences, attitude about mealtime (enjoyed? a time for playing? eat with others?).

B. Sleeping: difficulty going to sleep? wake in middle of night? nightmares? What do parents do when child can't sleep?

C. Elimination: what are the bowel movements like? prone to diarrhea?

D. Activity: active, inactive, hyperactive? Zestful? Invested in toys? Coordinated? Easily frustrated?

E. Social relationships: prefer certain people? fearful or shy of strangers? relationships with doctors, nurses, siblings, friends?

F. Language and communication: use of language to communicate needs, use of non-verbal means, amount of "jabbering."

- G. Social experiences away from home.
- H. Autoerotic and autoaggressive behavior.
- I. Fears, anxiety, unusual sensitivities.
- J. Aggressive behavior, including parental reactions and method of dealing with it.
- K. Parents' overall impressions of child: difficult? easy to care for? mood? personality traits? who he/she is like in the family? who was he/she named after? attitude toward defect? feeling about having more children?

XI. Parents' plans and expectations about the upcoming hospitalization. Will visit how often? Will room in? How do they feel about leaving child with nurses?

OBSERVATIONS

Recording will be done in five minute segments. For the first four minutes, I will make descriptive observations of the child in relation to her environment. During the fifth minute of each segment, I will rate the behavior of the previous four minutes along certain dimensions of infant behavior. These have been chosen from the dimensions of behavior described by Sybille Escalona (The Roots of Individuality) and with reference to the Yale Revised Developmental Schedule. The categories and rating system are as follows:

I. Gross Motor Activity

A. This refers to movement of the trunk, limbs, and neck, particularly the large musculature. It does not refer to "Fine Motor Activity" which refers to movements of the hands and feet, such as grasping, manipulating, or to hand-eye coordination. It includes locomotion but also movement of the gross musculature without locomotion.

B. Two characteristics of this activity will be rated:

1. Amount of activity
   a. Inactive or slight active = 0
   b. Moderately active to active = 1
   c. Hyperactive = 2

2. Amount of zest in the activity
   a. 0 = quality of activity is lifeless, lacking zest
   b. 1 = activity done with moderate amount of zest (or "animation," or "energy")
   c. 2 = activity performed with great zest.

C. Of course, there are five minute segments when two minute segments the child is zestful and hyperactive and for two other minutes the child is immobile, gazing or pondering, and therefore inactive and perhaps moderately zestful (assuming one can gaze with zest). In such a case I will try to make a general statement of the four minute segment, perhaps active and zestful; but if I feel that significant segments of listless or hyperactive behavior are lost that way, I will mention both ratings in the summary.

II. Interaction with toys and inanimate objects.

A. This refers to the child's investment in the "other than people" world. In the case of Brenda Kelly, it includes interaction with the German Shepherd, Tex.

B. Three characteristics of this activity will be rated:

1. Approximate duration, of the four minutes, that the interaction with toys or objects was occurring. This will be listed as _1_, _2_, _3_, or _4_ minutes.

2. Whether the interaction was initiated by the child or by someone (or in the case of Tex, Something. . .) else. The recording will be either _self-initiated_ or _other-initiated_. It is often difficult to sort out the initiator of an interaction such as this, as one could say each action is a new initiation or else a response to previous action by self or other. I tried to make the judgments only when it was a clear case that this child initiated play with a toy or the dog or whatever, or else that someone else or the dog clearly introduced a new object to play or interact with into the child's field of awareness (that is, interrupted or intruded). In cases where neither type of interaction predominated in the four minutes, but both occurred relatively in equal amounts. I recorded _self and other-initiated_.

3. Whether the interaction seemed to the child to be pleasurable _2_, neutral _1_, or unpleasurable _0_. This I judged not by how the interaction was intended by an adult or would seem as if it should have been for the child, but how the child looked and acted during the interaction.

4. As this category includes that characteristic, "attention span" or "ability to concentrate," I will when the child concentrates on one toy or task for more than a minute note that in the summary.

III. Interaction with people.

A. This refers to the child's involvement with the world of people and does not include only verbal exchanges, but also quiet playing, hugging, hitting,

and even the times when the child is watching and listening to people. In the categorization, however, it will be seen that this characteristic is looked at in two ways: (1) how much time was the child's awareness focused on people, and (2) how many times did the child initiate an interaction on her own versus how many times did the other person (usually adult) intrude into the child's ongoing stream of awareness and initiate the interaction.

B. Three characteristics will be rated concerning the four minute segments:

1. For how long was the child's awareness dominated by people: _1_, _2_, _3_, or _4_, or _0_ minutes.

2. Were more interactions clearly initiated by others or by the child: _self-initiated_ versus _other-initiated_. If there seemed to be an even balance, the summary is self- and other-initiated.

3. As with interactions with toys, a rating is given to whether the child found the interaction pleasurable _2_, neutral _1_, or unpleasurable _0_, based on the child's actual apparent state at the time.

IV. Affect and anxiety.

A. This is a rating that refers to the predominating mood or apparent feelings of the child during the four minutes. These are very broad ratings of whether the child was uncomfortable _0_, comfortable _1_, or clearly pleased _2_.

B. When there was a time during the four minutes that the child was either clearly very pleased or excited or happy, or clearly very upset or unhappy, the instances are noted in the summary.

V. Language and communication.

A. This will refer to the words and sounds that the child makes. It is rated as either _directed_, when it is clearly in order to evoke a response of some kind in the people around, or _non-directed_, when it seems to be an accompaniment of the child's play or whatever, not intended to evoke a response in another person.

B. The sounds and words will also be rated for whether there was a relatively _minimal_ amount, _moderate_ amount, or _great_ amount.

SCL-90

	Study	DDU Patient No.				Init.		Prog. Status			Day of Year			Year	
	A														
ol. No.	1	2	3	4	5	6	7	8	9	10	11	12	13	14	15

isted below are symptoms or problems that people sometimes have. Please read each one carefully and decide how much he complaint bothered or distressed you *during the past week, including today.* Then put a check mark (✓) in one of the ive boxes to show this.

low, If the symptom is "headaches," and headaches have bothered you *not at all,* put a check mark (✓) in the box in olumn 1 *(Not At All)* next to the word "headaches," If headaches have been bothering you *a little bit,* put a check mark n the box in column 2 *(A Little Bit).* If headaches have been bothering you *moderately*, put a check mark in the box n column 3 *(Moderately).* If headaches have been bothering you *quite a bit,* put a check mark in the box in column 4 *Quite A Bit).* Finally, if headaches have been bothering you *extremely*, put a check mark in the box in column 5 *(Extremely).*

EXAMPLE HOW MUCH WERE YOU BOTHERED BY	1 Not At All	2 A Little Bit	3 Moderately	4 Quite A Bit	5 Extremely
Backaches	☐	☑	☐	☐	☐
Headaches	☐	☐	☐	☐	☐
Nervousness or shakiness inside	☐	☐	☐	☐	☐
Unwanted thoughts, words, or ideas that won't leave your mind	☐	☐	☐	☐	☐
Faintness or dizziness	☐	☐	☐	☐	☐
Loss of sexual interest or pleasure	☐	☐	☐	☐	☐
Feeling critical of others	☐	☐	☐	☐	☐
The idea that someone else can control your thoughts	☐	☐	☐	☐	☐
Feeling others are to blame for most of your troubles	☐	☐	☐	☐	☐
Trouble remembering things	☐	☐	☐	☐	☐
Worried about sloppiness or carelessness	☐	☐	☐	☐	☐
Feeling easily annoyed or irritated	☐	☐	☐	☐	☐
Pains in heart or chest	☐	☐	☐	☐	☐
Feeling afraid in open spaces or on the streets	☐	☐	☐	☐	☐
Feeling low in energy or slowed down	☐	☐	☐	☐	☐
Thoughts of ending your life	☐	☐	☐	☐	☐
Hearing voices that other people do not hear	☐	☐	☐	☐	☐
Trembling	☐	☐	☐	☐	☐
Feeling that most people cannot e trusted	☐	☐	☐	☐	☐
Poor appetite	☐	☐	☐	☐	☐
Crying easily	☐	☐	☐	☐	☐
eeling shy or uneasy with the pposite sex	☐	☐	☐	☐	☐

HOW MUCH WERE YOU BOTHERED BY	1 Not At All	2 A Little Bit	3 Moderately	4 Quite A Bit	5 Extremely
37 Feeling of being trapped or caught	☐	☐	☐	☐	☐
38 Suddenly scared for no reason	☐	☐	☐	☐	☐
39 Temper outbursts that you could not control	☐	☐	☐	☐	☐
40 Feeling afraid to go out of your house alone	☐	☐	☐	☐	☐
41 Blaming yourself for things	☐	☐	☐	☐	☐
42 Pains in lower back	☐	☐	☐	☐	☐
43 Feeling blocked in getting things done	☐	☐	☐	☐	☐
44 Feeling lonely	☐	☐	☐	☐	☐
45 Feeling blue	☐	☐	☐	☐	☐
46 Worrying too much about things	☐	☐	☐	☐	☐
47 Feeling no interest in things	☐	☐	☐	☐	☐
48 Feeling fearful	☐	☐	☐	☐	☐
49 Your feelings being easily hurt	☐	☐	☐	☐	☐
50 Other people being aware of your private thoughts	☐	☐	☐	☐	☐
51 Feeling others do no understand you or are unsympathetic	☐	☐	☐	☐	☐
52 Feeling that people are unfriendly or dislike you	☐	☐	☐	☐	☐
53 Having to do things very slowly to insure correctness	☐	☐	☐	☐	☐
54 Heart pounding or racing	☐	☐	☐	☐	☐
55 Nausea or upset stomach	☐	☐	☐	☐	☐
56 Feeling inferior to others	☐	☐	☐	☐	☐
57 Soreness of your muscles	☐	☐	☐	☐	☐
58 Feeling that you are watched or talked about by others	☐	☐	☐	☐	☐
59 Trouble falling asleep	☐	☐	☐	☐	☐

HOW MUCH WERE YOU BOTHERED BY	Not At All 1	A Little Bit 2	Moderately 3	Quite A Bit 4	Extremely 5
60 Having to check and double-check what you do	☐	☐	☐	☐	☐
61 Difficulty making decisions	☐	☐	☐	☐	☐
62 Feeling afraid to travel on buses, subways or trains	☐	☐	☐	☐	☐
63 Trouble getting your breath	☐	☐	☐	☐	☐
64 Hot or cold spells	☐	☐	☐	☐	☐
65 Having to avoid certain things, places, or activities because they frighten you	☐	☐	☐	☐	☐
66 Your mind going blank	☐	☐	☐	☐	☐
67 Numbness or tingling in parts of your body	☐	☐	☐	☐	☐
68 A lump in your throat	☐	☐	☐	☐	☐
69 Feeling hopeless about the future	☐	☐	☐	☐	☐
70 Trouble concentrating	☐	☐	☐	☐	☐
71 Feeling weak in parts of your body	☐	☐	☐	☐	☐
72 Feeling tense or keyed up	☐	☐	☐	☐	☐
73 Heavy feelings in your arms or legs	☐	☐	☐	☐	☐
74 Thoughts of death or dying	☐	☐	☐	☐	☐
75 Overeating	☐	☐	☐	☐	☐
76 Feeling uneasy when people are watching or talking about you	☐	☐	☐	☐	☐

VISIT		78
FORM	5	79
CARD	1	80

16 Having thoughts that are not your own	☐	☐	☐	☐	☐
17 Having urges to beat, injure, or harm someone	☐	☐	☐	☐	☐
18 Awakening in the early morning	☐	☐	☐	☐	☐
19 Having to repeat the same actions such as touching, counting, washing	☐	☐	☐	☐	☐
20 Sleep that is restless or disturbed	☐	☐	☐	☐	☐
21 Having urges to break or smash things	☐	☐	☐	☐	☐
22 Having ideas or beliefs that others do not share	☐	☐	☐	☐	☐

HOW MUCH WERE YOU BOTHERED BY	Not At All 1	A Little Bit 2	Moderately 3	Quite A Bit 4	Extremely 5
23 Feeling very self-conscious with others	☐	☐	☐	☐	☐
24 Feeling uneasy in crowds, such as shopping or at a movie	☐	☐	☐	☐	☐
25 Feeling everything is an effort	☐	☐	☐	☐	☐
26 Spells of terror or panic	☐	☐	☐	☐	☐
27 Feeling uncomfortable about eating or drinking in public	☐	☐	☐	☐	☐
28 Getting into frequent arguments	☐	☐	☐	☐	☐
29 Feeling nervous when you are left alone	☐	☐	☐	☐	☐
30 Others not giving you proper credit for your achievements	☐	☐	☐	☐	☐
31 Feeling lonely even when you are with people	☐	☐	☐	☐	☐
32 Feeling so restless you couldn't sit still	☐	☐	☐	☐	☐
33 Feelings of worthlessness	☐	☐	☐	☐	☐
34 Feeling that familiar things are strange or unreal	☐	☐	☐	☐	☐
35 Shouting or throwing things	☐	☐	☐	☐	☐
36 Feeling afraid you will faint in public	☐	☐	☐	☐	☐
37 Feeling that people will take advantage of you if you let them	☐	☐	☐	☐	☐
38 Having thoughts about sex that bother you a lot	☐	☐	☐	☐	☐
39 The idea that you should be punished for your sins	☐	☐	☐	☐	☐
40 Feeling pushed to get things done	☐	☐	☐	☐	☐
41 The idea that something serious is wrong with your body	☐	☐	☐	☐	☐
42 Never feeling close to another person	☐	☐	☐	☐	☐
43 Feelings of guilt	☐	☐	☐	☐	☐
44 The idea that something is wrong with your mind	☐	☐	☐	☐	☐

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SCORING OF SCL-90 QUESTIONNAIRE

FACTORIAL COMPOSITION

I. Somatization (N=12)

Soreness of your muscles
Numbness or tingling in parts of your body
Heavy feelings in your arms and legs
Weakness in parts of your body
Pains in heart or chest
Hot or cold spells
Pains in lower back
Trouble getting your breath
Faintness or dizziness
A lump in your throat
Headaches
Nausea or upset stomach

II. Obsessive-Compulsive (N=10)

Having to check and double-check what you do
Having to do things very slowly to insure correctness
Your mind going blank
Trouble remembering things
Difficulty making decisions
Trouble concentrating
Worried about sloppiness or carelessness
Feeling blocked in getting things done
Having to repeat the same actions, i.e., counting, washing
Unwanted thoughts, etc., that won't leave your mind

III. Interpersonal Sensitivity (N=9)

Feeling critical of others
Feeling shy or uneasy with the opposite sex

III. (Cont'd.)

Your feelings being hurt easily
Feeling others do not understand you or are unsympathetic
Feeling that people are unfriendly or dislike you
Feeling inferior to others
Feeling uneasy when people are watching or talking with you
Feeling very self-conscious with others
Feeling uncomfortable about eating or drinking in public

IV. Depression (N=13)

Loss of sexual interest or pleasure
Feeling low in energy or slowed down
Thoughts of ending your life
Crying easily
Feelings of being trapped or caught
Blaming yourself for things
Feeling lonely
Feeling blue
Worrying too much about things
Feeling no interest in things
Feeling hopeless about the future
Feeling everything is an effort
Feelings of worthlessness

V. Anxiety (N=10)

Nervousness or shakiness inside
Trembling
Suddenly scared for no reason
Feeling fearful
Heart pounding or racing
Feeling tense or keyed up
Spells of terror and panic
Feeling so restless you can't sit still
Feeling that familiar things are strange or unreal
Feeling pushed to get things done

VI. Anger-Hostility (N=6)

Feeling easily annoyed or irritated
Temper outburst you cannot control
Having urges to beat, injure, or harm someone
Having urges to break or smash things
Getting into frequent arguments
Shouting or throwing things

VII. Phobic Anxiety (N=7)

Feeling afraid in open spaces or on the streets
Feeling afraid to go out of your house alone
Feeling afraid to travel on buses, subways, or trains
Feeling uneasy in crowds, such as shopping or at a movie
Feeling nervous when you are left alone
Feeling afraid you will faint in public
Having to avoid certain things, etc., because they frighten you

VIII. Paranoid Ideation (N=6)

Feeling others are to blame for most of your troubles
Feeling that most people cannot be trusted
Feeling that you are watched or talked about by others
Having ideas or beliefs that others do not share
Others not giving you proper credit for your achievements
Feeling that people will take advantage of you if you let them

IX. Psychoticism (N=10)

The idea that someone else can control your thoughts
Hearing voices that other people do not hear
Other people being aware of your private thoughts
Having thoughts that are not your own
Feeling lonely even when you are with people
Having thoughts about sex that bother you a lot
The idea that you should be punished for your sins
The idea that something serious is wrong with your body
Never feeling close to another person
The idea that something is wrong with your mind

X. SCL-90 Additional Scales

Poor appetite
Overeating
Trouble falling asleep
Awakening in the early morning
Sleep that is restless or disturbed
Thoughts of death or dying
Feelings of guilt

Reports of Scores in Chapters V and VI

Three types of scores are used in the reports. Each of the 90 items receives a score of 1, 2, 3, 4, or 5, meaning Not at all, A little bit, Moderately, Quite a bit, or Extremely. Scores of some individual items are reported, based on this scale. The Global Symptom Index, which is reported and graphed for each individual, is derived by summing the scores of all individual items and dividing by 90. A higher index naturally represents increased symptomatology. The Factorial Symptom Index is derived by summing the scores of all individual items included in one factor (e.g. Depression) and dividing by the number of items in the factor (e.g. for Depression, 13).

CHILD BEHAVIOR QUESTIONNAIRE

In the list below, we are asking you to describe how your child has seemed to you in the last two days. For example, if the statement applies to your child just a little bit during the past two days, check "just a little bit."

	Not at all	A little bit	Moderately	Quite a bit	Extremely
1. My child spends time sitting or lying and doing nothing.					
2. My child is full of energy and zest.					
3. My child is afraid of new things.					
4. My encouragement is necessary for my child to play with his/her toys.					
5. My child enjoys playing with toys.					
6. My child is interested in what the people around him/her are doing.					
7. My child does things to get my attention, rather than waiting for me to initiate play or talking.					
8. My child responds to my interests in doing things with him/her.					
9. My child tends to get into battles with me around the limits I set.					
10. My child gets upset when I leave him/her for a few minutes.					

	Not at all	A little bit	Moderately	Quite a bit	Extremely
11. My child follows me everywhere around the house.					
12. My child seems afraid of new places.					
13. My child is shy around or afraid of strangers.					
14. My child laughs often.					
15. My child cries often.					
16. My child has temper tantrums.					
17. My child seems comfortable.					
18. My child seems uncomfortable and irritable.					
19. My child seems happy a lot.					
20. My child seems unhappy a lot.					
21. It is difficult for me to get my child to talk with me.					
22. My child tries to tell me in words what he/she wants.					
23. My child babbles and makes sounds to other people.					
24. My child eats well.					
25. My child spits up food.					
26. My child finds mealtimes pleasurable.					

		Not at all	A little bit	Moderately	Quite a bit	Extremely
27.	My child is fussy at mealtimes.					
28.	My child has trouble going to sleep.					
29.	My child wakes up and cries at night.					
30.	My child sleeps with me.					
31.	My child takes nap at regular times.					
32.	My child needs certain toys or objects to go to sleep.					
33.	My child's stools have been unusually frequent.					
34.	My child's stools have been unusually watery.					
35.	My child's stools have been unusually hard.					
36.	My child's stools have been unusually infrequent.					
37.	My child enjoys diaper changes.					
38.	My child enjoys baths.					

Psychological Nurses' Notes, CCRC

The nurse caring for Gail Burns recorded observations after periods of, at the least frequent, every four hours, and at the most frequent, every one hour. The variation depended on the nurse's particular work load at that time. The categories of recorded behavior were designed by the nurses and myself in collaboration, including the most relevant behaviors within the context of this study, especially to be used in comparison with my own and others' observations. In each category, a nurse would freely record her observations, but always to include the following discriminations:

I. Activity of Child

- A. Sleeping/Awake, Alert/Awake, drowsy.
- B. Active and zestful/Active, without zest/Inactive

II. Investment in Toys

- A. Seems interested in toys on her own/Interested only if someone is initiating play/Seems not interested.

III. Emotional State

- A. Pleased, happy/Comfortable/Uncomfortable/Very uncomfortable.

IV. Communication (verbal)

- A. Crying/Babbling to self or toys/"talks" to me/"Talks" to mother/Only "talks" in response to other/Quiet.

V. Response to Me

- A. Frightened/Cautious/Indifferent/Friendly/Reaching for me or clinging to me/Other.

VI. Response to Mother

A. Affectionate/Indifferent/Demanding/Angry/Other.

VII. Comments about Mother.

A. Relaxed, "at home"/Tense, awkward, shy.

B. Responses to child.

C. Relationship to me.

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